

1. Positive wellbeing

Helping people to improve their mental wellbeing

Children and young people

Opportunities to develop positive mental wellbeing are vital to children and young people living with a terminal or life-limiting condition. To develop positive mental wellbeing, they need to be able to live life to the full, which means having access to opportunities to contribute to society and share their voices and stories. Such opportunities include paid employment, volunteering or group projects which boost morale.

Another opportunity for children and young people with a life-limiting condition to contribute to society is through art. For example, Together for Short Lives' 'This is Me' project created a space for children and young people to submit artwork such as poems, paintings and drawings to share how they feel about their life and how their health condition affects them. This project was set up in response to calls from children and young people who were looking for an outlet for artwork they create as a coping strategy. Projects that create opportunities for self-expression like 'This is Me' promote positive mental well-being among children and young people receiving palliative and end of life care and should be promoted across the country.

Social events are also an important part of supporting children and young people with a life-limiting illness to live life to the full and build positive wellbeing. Children's hospices often facilitate socialising by young people in their care as it can often be difficult for children with complex needs to socialise through traditional routes due to access requirements or a need to have medication or carers on hand. For example, Nottinghamshire Hospice runs a monthly young adults group, which provides service users with an opportunity to socialise with other young adults and access games, music, support and advice. The young adults group is aimed at the newly diagnosed or those transitioning from being under the care of a children's hospice to adult services. A participant in the group said "a lot of young people with life-limiting illnesses are behind socially because their disabilities prevent them from hanging out together and they feel vulnerable in mainstream social situations. In a safer environment like this where there is care on hand if we need it we feel more relaxed."

Both of the above examples of services that promote positive wellbeing among children and young people with life limiting illnesses are led by the hospice movement. Many hospices go above and beyond to provide services that help children and young people develop and sustain positive wellbeing. However, it is difficult for hospices to provide this high level of care in an unsustainable funding environment and with high demands on their services.

Prior to the pandemic, an average of 18% of children's hospice funding came from the Government, with adult and children's hospices across the UK having to raise £3.1m of charitable income every single day.

In 2020, COVID-19 restrictions and donor confidence prompted a funding crisis in the hospice sector, resulting in a 40% drop in hospice fundraising in 2020-2021. Government stepped in with emergency funding to purchase capacity from the sector, without which many hospices would have struggled to survive. However, this most welcome emergency funding has now ended and, without a sustainable funding model, hospices struggle to raise enough money to provide services that are vital to the mental health and wellbeing of their patients. Hospices need sustainable funding and long-term security in order to continue to run high-quality services and events, which promote positive mental well-being for their service users. This is why Hospice UK is calling on Governments to work with hospices and Hospice UK to develop a sustainable solution to hospice funding and ensure equity in the distribution of hospice funding.

Building a supportive environment where everyone is more equipped to talk about loss and provide informal bereavement support promotes better mental wellbeing and can reduce the likelihood of grief leading to or worsening mental illness. Developing an understanding of death, dying and grief at a young age enables children and young people to support their own bereavement needs and the needs of others, now and in the future. Therefore, death, dying and bereavement should be incorporated into the national curriculum and be included in statutory guidance on relationships education, relationships and sex education (RSE) and health education in primary and secondary schools. Teachers also need to be sufficiently supported to open up conversations around and feel comfortable talking about death, dying and grief with their students.

It is also vital that children and young people with terminal or life-limiting illnesses are not excluded from learning about mental health and wellbeing due to their condition. Hospices and other care providers should also be supported with the training and resources to have conversations about mental health and wellbeing with the young people in their care, adapted to their needs, as many of these children may be unable to regularly attend school.

Those more likely to experience poor mental wellbeing

Studies have shown that people receiving palliative or end of life care are more likely to experience mental ill-health or have additional challenges to their mental health. For example, an estimated 25% to 48% of advanced cancer patients experience significant anxiety symptoms. This has been linked to lower levels of quality of life, increased levels of insomnia, decreased trust in physicians and poor treatment compliance. Therefore, it is vital to promote positive mental wellbeing amongst those receiving palliative and end of life care and support them to improve their own wellbeing.

Having social events to look forward to is vital to maintaining your own positive wellbeing. However, for many adults with terminal or life-limiting conditions, it can be difficult to socialise or attend normal social events without support due to additional or complex needs, such as access needs and equipment or medication requirements. Many hospices run social events and groups that allow those with terminal or complex illness to socialise in a way which supports their needs. These events also often provide respite for carers, or an opportunity for them to speak with other carers with similar experiences, promoting positive mental well-being for them as well. To help people in palliative and end of life care improve their own wellbeing, Government and the NHS need to support hospices to deliver these crucial services. Hospices are best placed to offer these services, as they are often already linked in with patients and their families.

The lack of a sustainable funding model for hospices across the UK is a significant barrier to the delivery and long-term security of these day services. Prior to the pandemic, an average of 34% of adult's hospice funding came from the Government, with hospices across the UK having to raise £3.1m of charitable income every single day.

In 2020, COVID-19 restrictions and donor confidence prompted a funding crisis in the hospice sector, resulting in a 40% drop in hospice fundraising in 2020-2021. Government stepped in with emergency funding to purchase capacity from the sector, without which many hospices would have struggled to survive. However, this emergency funding has now ended and hospices continue to struggle to raise enough money to provide services vital to the mental health and wellbeing of their patients. It is also becoming increasingly difficult to fundraise to meet the demands of the UK's growing and ageing population, the increasingly complex needs of people who need palliative and end of life care and the rising need for end of life care in the community.

For many, activities that make us feel like valued members of society, such as paid employment or volunteer work are, key to maintaining positive mental wellbeing. However, too often people with a terminal or life limiting illness are signed off from work when they are able, and would prefer, to be working. It is important that employers support those with terminal or life-limiting illnesses to continue to work if they wish to do so, for example, with reasonable adjustments, such as flexible working hours. Employers should also build a compassionate culture and implement policies that support carers of people with a terminal or life limiting illness and people who have been bereaved to ensure they can live healthy and happy working lives.

Hospice UK's Compassionate Employer's Programme, is a workplace support programme that works with employers and their employees to build an open, compassionate culture to support staff who are grieving, have caring responsibilities, or have a life-limiting illness. The programme is focused on building a sustainable culture of compassion within organisations to support everything associated with death and dying in the workplace. Organisations that join this programme:

- are assessed against our criteria and given a Compassionate Employers bronze, silver or gold award as well as tailored recommendations for improvement that cut across policy, practical support and employee engagement.
- receive training workshops and webinars including, for example, Understanding Bereavement Workshops (both Foundation and Advanced) and Handling Difficult Conversations. The programme also provides specific training for line managers.
- have access to an online resources hub.
- have a dedicated account manager to support their needs and tailor their programme.

Government should promote initiatives such as Compassionate Employers as ways in which organisations can better support the mental health and wellbeing of their staff. They should also build a compassionate culture within public sector institutions, such as Government departments and the NHS. There is a clear opportunity to empower compassionate communities, by working with people and voluntary organisations to establish programmes that support one another, identifying early on where people might have a support need.

For many, feeling in control can be important to sustaining positive mental wellbeing, however, often conversations about the health and care someone wants to receive when they are dying happen too late or not at all. Advance care planning is the process of making decisions about what kind of care you'd like to have in the future. Being able to make decisions about your care and what is important to you, and know your options throughout your health and care journey allows a patient to take control and be prepared, thus promoting positive mental wellbeing for those with care needs or those who are receiving palliative or end of life care. It is vital that, throughout the health and social care system, the value of advanced care planning is understood and staff are trained to raise advance care planning early on in a patient's journey and support them through it.

It is important that the health and care system takes a preventative approach, providing early support, help with planning and good communication from professionals to make sure that people nearing end of life and their families do not experience poor mental wellbeing.

Hospices are typically small organisations rooted in their local community and therefore are well placed to assess and respond to the mental wellbeing needs of people with terminal and life limiting conditions and their families. There are numerous hospice provided resources and services designed to improve the wellbeing of people approaching the end of their lives, their carers and their loved ones. For example, 'Compassionate Neighbours', a social movement founded by St Joseph's Hospice in East London, trains volunteers to befriend and offer a listening ear to people at the end of life, through age or illness, living in their community. This service has been successful at improving wellbeing in the population by preventing loneliness and isolation and 'Compassionate Neighbours' has now been rolled out in hospices across the UK.

Hospices are typically small, community rooted and primarily charitably funded organisations. Whilst, this makes them well placed to respond to the needs of their community it creates specific challenges around ensuring the hospice is sufficiently funded, staffed and well-connected to the wider health and care system. For hospices to continue to provide essential services, innovate and develop new ways to improve the population's wellbeing, they require the security of a sustainable funding model.

Hospices are also experiencing a staffing crisis, which acts as a barrier to working better together across the system. A survey conducted by Hospice UK in Spring 2021, found an 11% vacancy rate in community-based and 7% vacancy rate in hospice-based nursing roles in adult hospices. However, these vacancies are representative of what is affordable within current funding rather than the level of staffing actually required to meet population need. Furthermore, since the above data was collected, it is clear that the staffing situation has worsened significantly. More recent research found that the average vacancy rate for nurses and other non-medical care and support professionals (at the equivalent of NHS Agenda for Change band 5-9) in children's hospices in England is 18.6%. To enable hospices to work better with health and care sector partners to improve the population's wellbeing, they need to be eligible for the same workforce opportunities as the NHS. For example, Government should encourage and support placements and apprenticeships in hospices and ensure all hospice staff and volunteers have access to NHS training opportunities.

2. Preventing the onset of mental ill-health

To reduce the number of people who experience mental ill-health we need to tackle taboos around death and dying to ensure that everyone who needs informal or formal bereavement support to prevent them from experiencing mental ill-health is able to access it.

Many people do not know how to approach conversations about death and dying and worry about not saying the right thing. People struggle to have conversations about death ahead of time, resulting in less advanced planning and more anxieties for the dying person and those around them. Additionally, people who have been bereaved can find it difficult to ask for support from their social networks or employer if conversations about death and dying are not normalised and, as a result, become more vulnerable to experiencing mental ill-health and needing formal professional bereavement and mental health support. To address this, the most important thing the Government could do is implement a national, funded, public campaign on bereavement to open up conversations around death and dying.

The role of employers

Employer support for people who have been bereaved to protect their mental health is more important than ever given the traumatic circumstances in which many employees lost loved ones during the pandemic. Currently, only 1 in 3 organisations have a dedicated bereavement policy in place and when a policy is in place, employees often say it reflects a 'hierarchy of grief', labelling some bereavements as

more deserving of support. Furthermore, despite the timeline of grief often being long and complicated, many bereavement support options only intervene at the point of death. Many employees on Hospice UK's Compassionate Employers programme have requested more support with anticipatory grief. Anticipatory grief is where the impact of grief is felt before a bereavement has occurred and is often experienced when the person dying is in receipt of palliative or end of life care. It is vital that line managers and colleagues be educated on the impact of anticipatory grief on the individual, their mental health and their performance.

Building a compassionate workplace culture is vital to protecting the mental health of employees and preventing caring responsibilities, bereavement or living with a terminal illness from giving rise to mental illness. Hospice UK's 'Compassionate Employers' programme, is a workplace support programme that works with employers and their employees to build an open, compassionate culture to support staff who are grieving, have caring responsibilities, or have a life-limiting illness. Organisations that join this programme:

- are assessed against our criteria and given a Compassionate Employers bronze, silver or gold award as well as tailored recommendations for improvement that cut across policy, practical support and employee engagement.
- receive training workshops and webinars including, for example, Understanding Bereavement Workshops (both Foundation and Advanced) and Handling Difficult Conversations. The programme also provides specific training for line managers.
- have access to an online resources hub.
- have a dedicated account manager to support their needs and tailor their programme.

By working with Compassionate Employers, employers can improve the support they provide to staff who are grieving, have caring responsibilities, or have a life-limiting illness and protect their mental health. Government should promote programmes and initiatives such as Compassionate Employers as ways in which organisations can better support the mental health and wellbeing of their staff.

UK employees have a right to a 'reasonable' amount of paid leave in the event of the death of an adult dependant but there is no minimum amount and this does not apply to the deaths of non-dependants. Two weeks of statutory paid bereavement leave is only available for employees who lose a child or suffer a miscarriage. Many employer bereavement policies also do not account for the death of a non-immediate family member. Employers must go much further than statutory minimum bereavement support requirements to ensure that their employees are able to take the compassionate leave they need. Government should also re-evaluate the current statutory workplace support available for people who are bereaved and explore how it can ensure individuals are better supported.

Government should also build a compassionate culture within public sector institutions. Specifically, there is an increased and ongoing need for health and social care employers including the NHS, to take additional measures to protect the mental health of the workforce. During the pandemic, health and social care workers were dealing with increased demand, and long working hours and many witnessed and experienced traumatic events. For example, generalist health and care staff, particularly those who were redeployed or working in care homes, had to deal with high volume of death with little to no previous experience or training in end of life care. Many senior nurses had the additional stress of having to police visitation, vaccination and other infection, prevention and control measures, as rules were altered at short notice, and manage the significant distress these measures were causing to staff, patients and loved ones. We know that this has resulted in some health and social care staff suffering from PTSD, heightened anxiety and other mental health challenges.

Government must offer training to all health and social care staff across the system on the bereavement and mental health support available, coping mechanisms for dealing with emotionally challenging events and how to spot when a colleague is struggling and signpost them to support. Facilitating good communication within teams, even when people may be working remotely, also helps to build peer

support. The Government also needs to support services specifically aimed at providing support to the health and social care workforce across the country and ensure they are consistently and sustainably funded.

There are significant workforce shortages in the palliative and end of life care sector, which alongside the increase in need during the pandemic, are leading to high levels of burnout and exhaustion among staff that deliver care for people who are dying. A March 2021 survey found an average 11% vacancy rate in community nursing roles for adult hospices and average 7% vacancy rate in adult hospice based nursing roles. These vacancies are representative of what is affordable within current funding rather than the level of staffing actually required to meet population need. Furthermore, since the above data was collected, it is clear that the staffing situation has worsened significantly. More recent research found that the average vacancy rate for nurses and other non-medical care and support professionals (equivalent to Agenda for Change band 5-9) in children's hospices in England is 18.6%.

Due to workforce shortages and the increased demand for end of life care during the pandemic, which has remained at a high level and is likely to continue to increase, staff are working long hours and experiencing exhaustion and an inability to prioritise and offer their normal standard of care. This is resulting in many experiencing feelings of guilt, anxiety and depression. To address this and prevent the onset of further mental ill-health amongst the health and social care workforce, and particularly the palliative and end of life care workforce, the Government needs to address the staff shortages. One way the end of life care workforce can be supported specifically is to ensure hospices have the sustainable and secure funding needed to match NHS pay, and terms and conditions. It is also vital that the hospice workforce is considered in all future national and Integrated Care System health and social care workforce planning and that planning be driven data on current and projected population need.

3. How can we all intervene earlier when people need support with their mental health?

In order for people struggling with their mental health to access support early, this support needs to be signposted to them at the earliest possible stage. This includes signposting to informal and formal bereavement support, particularly when there is concern that a bereavement may lead to long term mental health conditions such as PTSD or grief disorders.

Hospice UK estimates that more than 5 million people have been bereaved in the UK over the past 18 months, with many experiencing multiple bereavements. Due to pandemic restrictions, many people died in circumstances that can result in additional trauma for their loved ones, alongside grief. During the pandemic, many people died in circumstances against their wishes, in poor conditions and with unmanaged fear, pain and other negative symptoms. Many loved ones had to take on caring responsibilities and witness the most difficult aspects of death first hand. Others were unable to see loved ones before they died because they were in hospital unable to receive visitors. The pandemic also had a significant impact on funeral arrangements and arrangements for bodies at point of death. Aspects that can affect how a person copes with a loss, such as mental health or drug-related challenges, have also worsened for many. This means that the pandemic will have led to a higher percentage of bereavements with factors, such as trauma, that make the bereaved more susceptible to grief disorders and in need of mental health support.

This Plan should include a commitment to ensuring all health and social care staff across the system, including NHS and non NHS providers, have training on bereavement support. This does not need to be resource heavy, time-consuming training on all aspects of bereavement. The focus should be on the value of making an offer of support to the bereaved and signposting them to support, so that this can be done at the earliest point. Staff should also be trained in spotting the signs of a traumatic bereavement that may turn into complex grief and knowing what additional support the bereaved may need. They

should also be aware of what bereavement support exists in their local area and appreciate the value of non-clinical and informal support, such as local community groups and peer support opportunities, as well as formal bereavement counselling. Mental health challenges stemming from bereavement can arise at various points after a loss and learning to be aware of the impact of anniversaries or other important dates will also be important for staff.

Mental ill-health can be associated with grief and bereavement. For many, a bereavement will cause temporary wellbeing challenges associated with grief, but with access to social support and awareness of what help is available, this will not develop into more serious mental ill-health. However, where informal or formal support is not available or accessed temporary wellbeing challenges can give rise to mental ill-health.

As mentioned above, the entire health and social care workforce, not just NHS staff, should receive training on bereavement support. This does not need to be resource heavy, time-consuming training on all aspects of bereavement. The focus should be on the value of making an offer of support to the bereaved and signposting them to support, so that this can be done at the earliest point. Staff should also be trained in spotting the signs of a traumatic bereavement that may turn into complex grief and knowing what additional support the bereaved may need and what is available in their area. Mental health challenges stemming from bereavement can arise at various points after a loss and learning to be aware of the impact of anniversaries or other important dates will also be important for staff.

However, to identify and respond to the signs of grief related mental ill-health beyond the health and care system, there needs to be more open discussion about death, dying and bereavement throughout society. In order to improve access to bereavement support and help people better navigate loss, everyone must feel empowered to talk about death, dying and bereavement and able to identify when someone needs help. There is a clear need for a national, funded, public campaign on bereavement, much akin to recent mental health campaigns such as Every Mind Matters, to shift attitudes and raise awareness. Hospice UK's Dying Matters campaign, which has a good footprint and the backing and expertise of the end of life care sector, would be delighted to offer its support and platform to any such campaign. However, to shift national attitudes towards death, dying and bereavement to prevent the development of mental ill-health prompted by grief and better identify when someone is struggling, significant investment and expertise will be required

Older people

Many older people have become more isolated during the pandemic and have therefore experienced increased feelings of anxiety and depression as well as frailty and deterioration of physical symptoms. It is important that, going forward, Government help fund and facilitate services and activities that get older people out of the house and increase their communication with people who can both provide informal support and identify whether more formal mental health support is needed. 'Compassionate Neighbour' initiatives offered by hospices are a great example of services that support older people with wider health problems to access appropriate informal support at an early stage.

Those more likely to experience mental ill health

As mentioned earlier, people with terminal or life-limiting diagnosis and those receiving palliative and end of life care can be more vulnerable to mental ill health. One study found that patients with advanced or terminal cancer often experience anxiety surrounding the treatment process, disease progression, uncontrolled pain, dying, and uncertainty as to what happens after death. Another study found that participants receiving palliative care reported significantly higher levels of depression and even a desire for hastened death.

A public health campaign educating the public on mental health in palliative and end of life care, and signposting what support is out there, would help people with life limiting conditions could get appropriate mental health support. The earlier people understand the mental health and well-being aspects being diagnosed with a terminal or life-limiting condition, or coping with a loved one's diagnosis, the better positioned they are to manage their mental health and seek support when needed.

An important way to ensure patients with potentially terminal or life-limiting conditions receive mental health support when they need it is to connect them to a specialist palliative care service, such as a hospice, as early as possible after diagnosis. Having a relationship with a palliative and end of life care provider can help to manage uncertainty and facilitate nuanced conversations about prognosis and treatment. Sometimes a patient may be receiving treatment but with no clear prognosis or have to choose between potentially life-saving but extremely intensive treatment or moving onto a palliative care pathway. Hospices and other specialist providers can facilitate these discussions, support Advanced Care planning and ease the transition to palliative care. This can ease some anxieties around disease progression, treatment and uncontrolled symptoms. Having these conversations early on can also help with autonomy and helping people feel in control of their own care pathway, preventing the onset of mental ill health.

Furthermore, the care that hospices provide is truly holistic, person-centred and therefore often includes services that can prevent the onset of mental ill health, such as respite services or art therapy, as well as more direct mental health and wellbeing support, such as bereavement counselling. Hospices offer the expertise needed to support terminally ill patients through their illness and the mental health impacts of it but they require support and recognition by Integrated Care Systems to provide maximum value. Hospices must be valued as an integral part of the health and care system, including as part of the system of mental health support, and brought into ICS level conversations about the bereavement and mental health needs of their populations.

Children and young people

It is particularly important that children and young people with a life limiting condition get appropriate mental health support at an early stage if they are struggling. Children and young people are often more at risk of disengaging from services or providers when placed on long waitlists and deciding against accessing help/services. There is also a risk that a young person's needs will change quite rapidly or they will age out of a particular service and so interventions need to be applied when the need arises rather than further down the line. In order to identify the need for mental health support at an early stage, it is essential that children and young people with palliative and end of life care needs are provided with a space where they can be heard without their parents present. Often these young people are at a different stage of acceptance about their condition than their parents and have different concerns/worries that they may not want to share with their parents. Creating spaces where children and young people with life-limiting conditions can speak openly in a comfortable environment increases the likelihood of care providers identifying when a young person may need additional mental health support. Appropriate opportunities for talking therapies must be available to children and young people in palliative and end of life care and health and care providers must have access to referral routes to such services.

Early intervention bereavement support is also crucial for children and young people receiving palliative and end of life care. A lot of these young people's social connections will be made with other young people with life-limiting illnesses and therefore they can experience a higher volume of bereavement. This grief can also be complicated as it can make them reflect on their own condition. Palliative and end of life care services must be prepared and funded to implement regular age appropriate bereavement support, including activities such as memory books, which addresses the specific needs of this demographic. To do so it is vital that providers of end of life care to children and young people are supported to access specialist bereavement training alongside colleagues across the system and have the stable funding necessary to be able to provide these support services.

It is also vital that people at end of life are not impacted by long waiting lists when seeking mental health support. People with a terminal diagnosis should get priority access to support to ensure that they have a high quality of life in the time that they have left, particularly as there will be fast changing stressors on their mental health.

4. Improving quality and effectiveness

Children and young people

The quality and effectiveness of mental health and bereavement support for children and young people relies on timely access to age appropriate support. Providing support to a child or young person that is not adapted to the needs of their demographic, for example maturity, communication needs and social and personal circumstances, will cause them to disengage from support. It is therefore vital that support is provided to children and young people as soon as a need is identified and waiting lists are kept low by increases in funding for young people's mental health and bereavement services.

Currently, there is a big difference between what is available to children, young people and adults. In particular, eligibility criteria differ significantly for adult services. This means that there is often a large deficit in what support someone will receive once they reach 18 years of age. This often results in young people falling through the cracks when they are no longer eligible for children's services but not accepted by adult's services. This is a problem for all children and young people with mental health support needs, but it has a particular and significant impact on young people with terminal and life limiting conditions. Children and young people with terminal or life-limiting conditions can also benefit from access to support services specific to their experiences, such as meeting with young people with conditions similar to themselves. This may not be appropriate for everyone but is an important service that should be available.

To ensure that the best care and treatment is available widely on the NHS, and that no young person slips through the cracks of available care and support, special attention must be paid to transition points between services. The NICE national framework for transition includes a vision to ensure young people are no longer lost in transition between services by the year 2028. To achieve this, the organisation has recommended involving young people and their carers in service design, delivery and evaluation and ensuring that service managers in both adults' and children's services, across health, social care and education, proactively identify and plan for young people in their locality with transition support needs. Following these recommendations will improve the quality and effectiveness of mental health services offered to children and young people, and we hope they are taken into consideration at all levels of health and social care provision.

Working age adults

To ensure the best care and treatment for bereavement and associated mental ill health is widely available within the NHS, the NHS needs to be driven by the findings of research in this area and commit to year-on-year improvement of services using quality improvement methodology. Quality improvement methodology can be used to both improve and expand the reach of bereavement services. For example, in 2020/21, over a six-month period, Hospice UK supported nine hospices across England to rapidly prototype models of bereavement support using quality improvement methods to trial and measure the impact of 21 discrete projects. Through this project, within 6 months, at least 273 bereaved people received direct virtual support from hospices and 187 people gained greater skills and knowledge about supporting people who have been bereaved.

Throughout the pandemic, many mental health services were moved online in order to continue to offer support and keep people safe. For many, this meant they could continue to access vital support when they needed it most. This shift towards online provision also helped services, including many developed

within Hospice UK's bereavement support quality improvement project, to increase their reach. However, online services are not accessible to all. Those living in rural areas or in poverty may not be able to access stable internet connection or the materials required to participate in online services. Also for many groups, particularly older people, there is a lack of digital literacy or comfort with digital services that may prevent them being able to use these services. It is therefore important that the NHS ensures mental health and bereavement services do not remain exclusively online, and that services are made accessible to all through a range of online, telephone and in-person services as well as a mix of group and individual sessions.

Currently, the funding for the bereavement support sector is insufficient. Both in and outside of the pandemic, there is always a percentage of the population that is grieving and therefore a need for a constant and consistent level of funding for bereavement support. However, services are often implemented and then ended in quick succession due to inconsistent funding. There is a need for consistency and for useful services at all levels to receive adequate funding. Funding should include funding for local, informal support services within the community, including those offered or facilitated by hospices such as grief cafes and support groups.

Furthermore, it is vital that the level of funding for bereavement support be driven by data on local population need. Data needs assessments should be done routinely for each local population and, to achieve this, data collection on the provision of bereavement support needs to be brought up to speed.

It is essential that Government, and other health and care sector partners work across the system to ensure the best care and treatment is widely available, regardless of provider. Hospices deliver essential palliative and end of life care, including bereavement and mental wellbeing support for patients and their families. A person with a life limiting condition and their loved ones are likely to receive care from multiple providers across the system, including a hospice, making partnership working and integration key to ensuring they receive the best care available. In order to work closely together to deliver personalised care and support around the patient, hospices need to be recognised as a key part of the health and social care system by national Government and NHSE and have a voice within Integrated Care Systems. Data on hospice services must also factor into assessments of bereavement need and provision and the hospice sector bereavement support workforce must receive the same training and development opportunities as their NHS counterparts.

Furthermore, during the pandemic, many hospices opened up their bereavement support services to anyone in the local area or who had a loved one cared for by their services. A sustainable funding solution for the hospice sector is needed to ensure hospices can continue to provide these services and have the long term financial security to improve their quality and effectiveness.

For the best care and treatment to be widely available within the NHS, mental health and bereavement services need to be accessible to, and adapted for, groups which are more likely to experience mental ill-health or less likely to benefit from normal support services. For example, there is a need to establish bereavement support across the prison estate. Prison is an environment of enduring loss, with people in prison losing their liberty, time on the outside, access to close social networks and family ties and their own autonomy. Factors such as the lack of space to grieve in prison and restrictions on attending funerals and visiting dying family and friends can exacerbate and complicate grief. Ongoing and important work to develop bereavement support guidance for prisons and their staff should continue and funding should be available to develop this work further and ensure that both informal and formal bereavement services are available to people in prison and prison staff.

There is inequity in access to mental health and bereavement support and a need for inclusivity at all levels, for example, in the messaging and information shared. Currently, many groups and communities, such as people with cognitive disabilities or who are autistic, are not provided with accessible and genuinely helpful services. An example of good practice in improving access for this group is Mary

Stevens Hospice's 'No Barriers Here' project. Mary Stevens Hospice developed group creative sessions, with the help of an art psychotherapist, which allowed people with cognitive disabilities and who are autistic to explore feelings of loss and grief as well as their own understandings of what a good death looks like. Projects like this, which are co-produced with members of the community they serve, should be replicated across the UK. Furthermore, decisions around what bereavement support to offer and how to reach excluded communities are often made by individuals with no connection to these communities. People from under-served communities need to be involved in decision making regarding what services are offered in a meaningful way and funding needs to be available to make this happen.

The NHS has done well both to push mental health higher up the agenda, and to support public conversations and awareness around the challenges people might face. This has opened up conversations and has set very good ground work for even further conversations around mental health as it relates to death, dying and bereavement.

Priorities for future research, innovation and data improvements

The level of complex grief and bereavement as a result of the pandemic, and the mental health impact of that – both immediate and delayed – needs to be measured. We need a better idea of how many people are, and will be, impacted by this in order to act upon it and provide the right level of support. This is necessary both in the wider population and within the health and social care workforce.

As discussed throughout, those approaching the end of life, their loved ones and their carers are more likely to experience mental ill health. To drive better treatment outcomes for this group, hospices need to work closely with the rest of the health and care system and be supported to share data with the NHS. Government and NHS England and Improvement need to work with the sector to develop consistent standards for collecting and reporting data, and for describing the range of services that hospices provide and the people receiving care. Commissioners also need to build investment in information infrastructure, including staff skills, from data collection through to analysis and reporting into their funding arrangements with hospices.

Better data sharing would improve assessments of population need for end of life care, and the mental health needs of this demographic. Without an awareness of this population need within the health and care system, people with a life limiting illness and their families will not receive the mental health and bereavement support they need.

It is also vital that effective data collection is applied particularly for people in communities often underserved by healthcare.

5. Supporting people to live well

Creating a culture where we are comfortable talking about death and dying is critical to supporting people with their grief and preventing the onset of mental ill health after a bereavement. Across the UK, people need to have more open conversations about death, dying and bereavement so that people who have experienced a bereavement feel more supported by their peers and loved ones, and are able to ask for support when they need it. Hospice UK's Dying Matters campaign found that around 75% agreed to some extent that society would be happier if people were more willing to talk about death. However, results suggest that while most people want to offer support and talk about grief and bereavement, they would not feel confident enough to do so.

There is a clear need for a national, funded, public campaign on bereavement, much akin to recent mental health campaigns such as Every Mind Matters, to empower communities to talk about death and dying.

Hospice UK's Dying Matters campaign has a good footprint and the backing and expertise of the end of life care sector, so could offer a platform and its learning to any such campaign. However, to shift attitudes towards death, dying and bereavement to prevent the development of mental ill-health and better identify the signs when someone is struggling, significant investment and expertise will be required.

To support people with mental health conditions to live well, it is important those with mental health conditions or struggling with pressures on their mental health are supported in the workplace. Hospice UK's Compassionate Employers programme helps employers improve their support for staff affected by terminal illness, caring responsibilities and bereavement. More employers need take part in initiatives such as Compassionate Employers to foster a proactive, positive environment where supporting a colleague is no longer awkward or uncomfortable. Instead, supporting a colleague affected by death, dying and bereavement can become a normal and even rewarding part of being at work, where difficult or challenging conversations are handled with warmth and understanding.

Improving the physical health of people living with mental health conditions

Support needs to be improved for people living with a mental health condition and receiving palliative and end of life care to ensure they can live and die well. There is a lack of data on how many people with severe mental health issues need palliative care. However, we know that, on average, people with severe mental disorders tend to die earlier than the general population. People with pre-existing mental health problems who develop a terminal illness and require end-of-life care are currently underrepresented in conversations about palliative and end of life care. National Government and the NHS should support palliative and end of life care providers to adapt their care for this cohort through national funding, guidance and funding.

Treating physical illness in people with mental health issues can be challenging as people experiencing mental distress may not understand the diagnosis, particularly if care providers are not trained to explain it to them, or be able to engage with medical practitioners. A person's existing psychiatric symptoms can be made worse by physical illness. The development of multidisciplinary teams, good communication and effective partnerships between health and care professionals working in both end of life and mental health care is essential to improving palliative and end of life care for those with severe mental illness.

Many hospices are connected with mental health care teams in their area and offer some form of psychological support. However, there needs to be closer partnership working between NHS mental health professionals and the hospice sector for hospices to access the specialist mental health understanding needed to adequately support people with both palliative and end of life care and mental health support needs. To improve mental health support for this group, it is also vital that mental health and palliative care, including end of life care and bereavement, be a core element within training curriculums and continued professional development and training for the health and care workforce.

It is also important that providers of specialist mental health support have an awareness and understanding of anticipatory care planning in order to identify when a patient in their care may need this support. The earlier conversations about end of life care can take place, and the better adapted to the patients' needs these conversations are, the more this eases pressures on the patient in the last months/weeks of life. It is also important that specialist mental health teams are supported to develop strong links with palliative and end of life care services to facilitate better provision of care around the patient.

To improve quality of life for people living with mental health conditions who have palliative care needs or are nearing end of life, mental health services need to be integrated with hospices and other palliative and end of life care providers. Integrated Care Systems need to recognise the value of hospices within their areas and ensure they have a voice within the system and are linked into other services their patients might be using or may require. Providers of specialist end of life care, such as hospices, also need to be

supported to build relationships with NHS mental health teams so they can work together to provide the best care for patients under their care.

6. Developing a Mental Health Plan

Patient-centered care and co-production should be at the centre of this plan. It is essential that care be built around service users, regardless of the number of providers involved, and that people with lived experience are able to share their perspective and be involved in the development of care and treatment to ensure that it properly addresses their needs.

This plan should take a cross-sector approach and include a consideration of voluntary and community organisations that deliver mental health and well-being support or care for people who are more likely to need this support, such as hospices. The plan and any delivery that results from it should also draw on the expertise of hospices and other voluntary organisations to address the critical need for bereavement support. Furthermore, the corporate world should also be addressed in this plan and involved in its implementation, as employers will play an important role in protecting positive mental well-being and supporting employees who are experiencing mental ill-health, particularly those who have experienced a bereavement.