Response to the Department for Health and Social Care's **"Mental health and wellbeing plan: discussion paper" (2022)** Care Not Killing & Our Duty of Care

Our questions for you

We need your support and ideas to develop a comprehensive plan that will help set and achieve our vision for mental health in 2035. We have chosen, in consultation with stakeholders and people with lived experience, to focus our questions on 6 key areas. These are:

- 1. How can we all promote positive mental wellbeing?
- 2. How can we all prevent the onset of mental health conditions?
- 3. How can we all intervene earlier when people need support with their mental health?
- 4. How can we improve the quality and effectiveness of treatment for mental health?
- 5. How can we all support people with mental health conditions to live well?
- 6. How can we all improve support for people in crisis?

The chapters in this paper provide more context for why we have focused on these areas, and set out the key challenges that will need to be addressed through a 10-year plan. For each area, we are seeking your views on a range of questions which stakeholders and people with lived experience of mental health conditions have identified as priorities. We are keen to hear about examples of best practice and innovation, including uses of digital technology and data.

How to respond

You can respond to any or all questions using the <u>online survey</u> by 11:45pm on 7 July 2022.

If you have any technical problems with using the online survey, log the issue by emailing mhplan@dhsc.gov.uk. Please do not send any personal information to this email.

To drive a step change in mental health outcomes, we need collective action across society. As individuals, friends, family members, carers, co-workers, community leaders and business owners, we all have the power to make a difference. We all have mental health, and all have a part to play in changing things for the better.

We will therefore be engaging widely to develop this plan and build consensus around the priority actions which need to be taken. Written responses will be supplemented by engagement with people with lived experience of mental ill-health, round tables and workshops with stakeholders from the voluntary sector and the clinical, teaching, social care, and business and tech communities. You can find a quick read version of this document and an easy read version.

Chapter 1: how can we all promote positive mental wellbeing?

Question: How can we help people to improve their own wellbeing?

Your ideas may include actions which can be taken by different types of organisations – such as national and local government, public services such as schools, and the NHS, employers and the private and voluntary sectors. It can also include things that happen between family members and local communities.

Please provide your suggestions in relation to the wellbeing of different groups:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) People that are more likely to experience poor wellbeing (see Annex A)

Question: Do you have any suggestions for how we can improve the population's wellbeing?

This can include ideas about what local people and communities can do together, as well as things you want to see in health services, wider public services such as education settings, places of employment and the private and voluntary sectors.

Please provide your suggestions in relation to the wellbeing of different groups:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) People that are more likely to experience poor wellbeing (see Annex A)

Question: How can we support different sectors within local areas to work together, and with people within their local communities, to improve population wellbeing?

This includes a wide range of public services, including education settings, social care, the NHS, voluntary sectors, housing associations and businesses.

Chapter 2: how can we all prevent the onset of mental ill-health?

Question: What is the most important thing we need to address in order to reduce the numbers of people who experience mental ill-health?

This might include actions which can be taken by national and local government, public services such as education settings, social care, the NHS, and the private and voluntary sectors.

Please provide your suggestions in relation to different groups:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) People that are more likely to experience mental ill-health (see Annex A)

Central to our submission will be two key messages:

1.the need to recognise and respond to the relationship between mental ill-health and physical illhealth; and

2.the need to state that all lives are equally valuable. No suicide is less tragic than another.

It is encouraging that in both the introduction and chapter two, "long-term physical health conditions" are included among "factors with the strongest evidence demonstrating links to the development of mental health conditions", although in both cases, such conditions are listed last, essentially as "also rans" or "honourable mentions". The revision of the suicide prevention plan and broader mental health responses provides an opportunity to reject suggestions that mental ill-health is inevitable when chronically/terminally ill or disabled, and thus less deserving of targeted interventions. For example, in the introduction, we learn that "two-thirds of people who end their life by suicide are not in contact with NHS mental health services." Will revised guidance state explicitly that those expressing suicidal ideation should have access to mental health services regardless of any physical ailment?

The aim is laudable: "We need to take a radical new, truly cross-society approach to promoting wellbeing, preventing mental health conditions, intervening earlier, improving treatment, supporting people with mental health conditions to live well and preventing suicide. We need to set a vision for change that can be 'made real' in each local area, transform lives and livelihoods..." This will mean nothing if at the end of the process, healthcare professionals and civil society accept suicidal ideation within certain groups (terminally ill, chronically ill, long-term disabled, mentally ill...) as reasonable and even to be facilitated. Not least because in singling out certain groups and characteristics, all who share those characteristics become devalued within society. We have primarily in mind attitudes concerning assisted suicide, but also consider what has been written towards the end of chapter two: "entrenched disparities, which may have been widened by the pandemic, that make it more likely some groups... will be exposed to risk factors for mental ill-health and suicidality." In 2020, a national scandal emerged as general practices and residential institutions placed DNACPR orders on the files of older, chronically ill and developmentally disabled people, ostensibly in expectation of coronavirus overwhelming NHS capacity. Both the fact and manner of these moves sent a clear signal that some lives were less valued than others. Mental health and suicide prevention support must include those who are physically unwell. (In this, we note the consultation paper's concession that "impacts on mental health are not always factored into decision-making on relevant national and local government policy areas.")

Question: Do you have ideas for how employers can support and protect the mental health of their employees?

Question: What is the most important thing we need to address in order to prevent suicide?

This might include actions which can be taken by national and local government, public services such as education settings, social care, the NHS, and private and voluntary sectors.

Please provide your suggestions in relation to different groups:

- a) Children and young people
- b) Working age adults
- c) Older adults
- d) People that are at greater risk of suicide (see Annex A)

Care Not Killing and Our Duty of Care were set up to refute arguments for the legalisation of assisted suicide and euthanasia. In the UK, these are proposed primarily in the context of terminal illness, chronic illness and disability and so our comments are particular to those situations.

Broadly speaking, expressions of a wish to die mostly subside when existential concerns and fears are addressed: when it becomes clear that most pain can be managed, when patients learn that they can remain in their own home, when their loved ones receive support in their caring responsibilities. One of the critical needs is to ensure equal access to well-resourced palliative care: Professor The Baroness Finlay of Llandaff told the House of Lords in 2019 that "an estimated 92,000 people each year in England would benefit from palliative care but do not receive any at all, either from specialist palliative care professionals or generalists. The family suffers too: 83% of carers—around 400,000 people per year—suffer significant psychological morbidity. Some of them are child carers. Cicely Saunders, the founder of the modern palliative care movement, said that the way a person dies lives on in the memory of those left behind. When a child is not adequately prepared for loss and sees clinical services fail to respond because they are not available seven days a week, their trauma is compounded."¹

The needs of those with chronic health conditions can be ignored even more easily. Chronic pain is harder to treat than acute pain and the services for people with chronic pain have long waiting lists. Leaving people in severe pain for months and years before they can access specialist treatment is not reasonable, and is a classical risk factor for suicidality. The same is true for those with chronic breathlessness, immobility or who live with chronic organ failure. Because these conditions receive less media coverage than illnesses like cancer, they also receive fewer services.

Services have been cut back both before and during COVID and need to be restored. We are aware of numerous disabled and/or elderly people who are trapped in their homes for want of support workers to help them access the community, or for want of day services where they can socialise. Social services now only provide help for urgent and severe problems, leaving many disabled individuals stuck at home without the support they need to lead lives they would consider worth living. Where individuals are housebound, lonely and unable to access services, there is a high risk of suicidality, with or without depression.

Turning to specific examples laid out in the consultation, we note concerns "about misleading and dangerous online content that encourages and facilitates eating disorders, self-harm and suicide". Much of this discourse concerns suicide-related internet use by young people; we applaud all efforts to combat this danger for our young people, but the risk of suicidal contagion also affects those with physical/mental/cognitive illnesses or disabilities. There is significant evidence of exposure to material about suicide sparking suicidality in others (the Werther effect).

• Australian assisted suicide activist Philip Nitschke, author of the regularly updated *Peaceful Pill Handbook*, advises his organisation's members on how to source lethal barbiturates; sells test kits so members can check the purity and potency of recommended, controlled Class B drug in their own homes; provides instructions on how people can gas themselves using a 'DIY' kit; and gives tips on how those assisting a suicide might avoid prosecution. His handbook is disseminated online, and he has also hosted workshops in London² but has avoided serious police investigation despite declaring "someone needs to provide this knowledge, training, or recourse necessary to anyone who wants it, including the depressed, the elderly bereaved, [and] the troubled teen. If we are to remain consistent and we believe that the individual has the right to dispose of their life, we should not erect artificial barriers in the way of sub-groups who don't meet our criteria."³ A prime example of police, health and social care needing to work together in opposition.

² <u>carenotkilling.org.uk/articles/importing-death/</u>

¹ hansard.parliament.uk/lords/2019-06-14/debates/42F5A25C-76C0-4542-B8CA-E3625E2C096A/AccessToPalliativeCareBill

³ web.archive.org/web/20140209184029/http://old.nationalreview.com/interrogatory/interrogatory060501.shtml

- Across the media more broadly, there is a need to recognise the "Werther effect." World Health Organisation guidance published in 2017⁴ states that: "vulnerable individuals are at risk of engaging in imitative behaviours following media reports of suicide, particularly if the coverage is extensive, prominent, sensational, explicitly describes the method of suicide, and condones or repeats widely-held myths about suicide. The risk is particularly pronounced when the person who died by suicide had a high social status and/or can easily be identified with. Reports about suicide that trigger subsequent suicides are often repeated over a longer period. The effect of media reports on increasing suicides is referred to as the "Werther effect", after an 18th century novel "The Sorrows of Young Werther" sparked a wave of suicides across Europe. Systematic reviews of studies in the area of media and suicide have consistently reached the same conclusion: media reporting of suicide can lead to subsequent increases in suicidal behaviours. If the revised guidance is to reach across society to forge a more coherent approach to suicide prevention, media relations are key, with energy devoted to counselling caution for news and dramatic portrayals. With regard to depictions of suicides or assisted suicides of those with terminal/chronic illnesses and disabilities, attention must be paid both to not publicising means and to not suggesting that if a viewer is in the same situation, that this is an expected response (as can be the perception when terminally ill characters are seen to end their lives.)
- Given that the guidance under review is destined to be in place well into the next decade, it is worth considering evidence pertaining to policy developments some campaigners would wish to see in that period notably the legalisation of assisted suicide in certain circumstances. Paton and Jones (2022) have written that "legalising euthanasia or assisted suicide (EAS)... is followed by considerable increases in suicide (inclusive of assisted suicide) and in intentional self-initiated death. There is no reduction in non-assisted suicide relative to the most similar non-EAS neighbour and, in some cases, there is a relative and/or an absolute increase in non-assisted suicide. Furthermore, the data from Europe and from the U.S. indicate that it is women who have most been placed at risk of avoidable premature death."⁵

Chapter 3: how can we all intervene earlier when people need support with their mental health?

Question: Where would you prefer to get early support for your mental health if you were struggling? Please tick all that apply.

- from family and friends
- from the NHS
- from your local authority
- from an education setting
- from a social care provider
- in your community
- from the voluntary and community sector
- from your workplace
- from digital-based support or advice
- from the private sector, for example by paying for counselling
- don't mind as long as the support is high-quality

⁴ apps.who.int/iris/bitstream/handle/10665/258814/WHO-MSD-MER-17.5-eng.pdf

⁵ jemh.ca/issues/open/documents/JEMH%20article%20EAS%20and%20suicide%20rates%20in%20Europe%20-%20copyedited%20final.pdf

• other – please specify

The consultation authors are correct to state that "the 'right' support will depend on someone's individual needs, how those needs affect them, the severity of their symptoms, their individual strengths, and their wider circumstances. Sometimes the most appropriate intervention will include providing support and information to important people in a person's life, such as parents, unpaid carers, teachers, families or employers. In some cases, interventions to tackle the triggers of a person's distress, or encouraging them to access activities which improve mood and wellbeing such as the arts, physical activity, or nature, may be most effective."

With respect to "important people in a person's life", we point to what is called the "burden of witness" – the suffering of those who observe loved ones in pain and distress, including in situations where carers fear the person's suffering is even greater than the reality (*cf* Professor Rob George, 2013⁶). The mental strain of living with a serious physical illness can be deepened by knowing that loved ones are suffering alongside, and that knowledge can in turn foster a sense that death would be preferable to the patient's own illness, causing others distress or inconvenience. More than 54% of those dying by assisted suicide in Oregon in 2021⁷ cited fear of being a "burden on family, friends/caregivers". All of this means that not only must patients receive better palliation and carers receive better respite, but loved ones must also be able to see and understand the care provided and the options available, to head off a cyclical sense that death might be a better option than life.

The reference to "encouraging them to access activities which improve mood and wellbeing such as the arts, physical activity, or nature" is also relevant to the international experience of assisted suicide: again, Oregon 2021, 93.3% mentioned "losing autonomy", 92% being "less able to engage in activities making life enjoyable." As with palliative care, a lack of access to (for example) favoured activities can usually be (at least partially) reversed if the person has access to suitable support and services. Given that these are far more of a driving force for assisted suicide than concerns about pain control (26.9%), the renewed suicide prevention guidance must take into account the existential concerns of those with physical illnesses.

Question: What more can the NHS do to help people struggling with their mental health to access support early?

Please provide your suggestions in relation to different groups:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who face additional barriers to accessing support for their mental health

Question: Do you have any suggestions for how the rest of society can better identify and respond to signs of mental ill-health?

- yes
- *no*

⁶ web.archive.org/web/20160429164124/http://faithdebates.org.uk/wp-

content/uploads/2013/09/1367921574_WFD2013_Assisted_Dying-_George.mp3

⁷ <u>carenotkilling.org.uk/articles/oregon-2021-anorexia-hernias-feeling-a-burden/</u>

If yes, please share your ideas.

You might want to consider community bodies, public services and private and community sectors. We are particularly interested in how society and different sectors can work together to get people support early.

Please provide your suggestions in relation to different groups:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who face additional barriers to accessing support

Question: How can we ensure that people with wider health problems get appropriate mental health support at an early stage if they are struggling?

You might want to consider barriers faced by individuals, as well as how health and social care services engage with those people.

Chapter 4: how can we improve the quality and effectiveness of treatment for mental health conditions?

Question: What needs to happen to ensure the best care and treatment is more widely available within the NHS?

We want to hear about the most important issues to address in order to improve NHS mental health care and treatment over the next 10 years.

We would be grateful for views on:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who report worse experiences and outcomes from NHS mental health services (see Annex A)

Question: What is the NHS currently doing well and should continue to support people with their mental health?

In our context of mental health, with respect to terminal and chronic illness, palliative care teams are crucial in supporting patients towards the end of their life cope with loss, pain, distress and helping them adjust to live well in the last few months of their lives.

Bereavement services are an important part of this care and may be provided by hospices. One example would be the Rowans Hospice in Portsmouth which has excellent access to psychological services which are part funded by the NHS.⁸

⁸ rowanshospice.co.uk/care/bereavement-services/

Another example would be the NHS Macmillan Unit in Bournemouth.⁹ The original unit was built in 1974 and referrals have tripled in the last 10 years. They are currently fundraising for £12 million for a new building. This service should be core provision by the NHS, not simply funded by donations.

Question: What should be our priorities for future research, innovation and data improvements over the coming decade to drive better treatment outcomes?

We would be grateful for views on priorities for research across the life course, including:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who have worse experiences in NHS mental health services, and/or often do not experience good outcomes (see Annex A)

We urge cooperation between research institutions focussing on different forms of ill-health (we have particularly in view, palliative care and mental health coming together) to ensure that these interwoven needs are seen in their proper context and treated effectively.

We also need research into the chronic conditions which undermine people's wellbeing, are usually comorbid with other long term conditions, and are poorly served. Untreated, these can predispose people to depression and to suicidality. Sadly, research tends to look at single conditions, and trials specifically exclude those with more than one major illness. This makes trial participants very different from those in a normal NHS or GP clinic and we have to tackle this.

We recognise and lay emphasis on the following from Annex A: "a review of evidence by the National Institute for Healthcare Research found that the healthcare system frequently fails to respond to the needs of people with multiple long-term conditions and focuses on individual diseases or issues resulting in complex, uncoordinated pathways. People with multiple long-term conditions feel their mental health and emotional wellbeing is frequently ignored, which often results in a worsening of symptoms."

Question: What should inpatient mental health care look like in 10 years' time, and what needs to change in order to realise that vision?

In the context of terminal illness, psychological services should be provided by specialist palliative care doctors and nurses in a hospice or hospital setting. For complex cases, clinical psychologist care will also be helpful. A multi-disciplinary approach is most helpful. Psychiatry services are uncommonly required but access can nonetheless be unduly difficult.

An outline of the role for psychologists in palliative care is described by the American Psychological Association.¹⁰ An example of basic integrated care can be seen in Norwich.¹¹

Core NHS funding should be supporting these services and ensuring equal access across the country.

⁹ <u>uhd.nhs.uk/services/palliative-care/macmillan-unit</u>

¹⁰ apa.org/monitor/2022/07/feature-palliative-care

¹¹ norfolkcommunityhealthandcare.nhs.uk/psychological-service-for-specialist-palliative-care

Chapter 5: how can we all support people living with mental health conditions to live well?

Question: What do we (as a society) need to do or change in order to improve the lives of people living with mental health conditions?

You might want to consider priorities at national and local government, wider public services such as social care and education settings, and the private and voluntary and community sectors

We would be grateful for input relating to:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who face additional barriers to accessing support

Recognising and diagnosing mental ill-health is an essential first step. Professor The Baroness Hollins has written that: "researchers have found that some patients who have ended their lives under the terms of Oregon's assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity, it is common in elderly people and it is treatable. But in some cases in Oregon it has not been diagnosed by the doctor who assessed the patient's capacity and prescribed lethal drugs. Oregon's law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened."¹² If those with terminal illnesses are not to receive second-class consideration, symptoms of mental ill-health must not be written off as simply feeling down about a physical diagnosis – they need and deserve fuller assessment, and treatment.

We also need to give people with long term illnesses the tools and services they need to access the community and play a part in society. These may be services such as access to chronic pain clinics (which include psychology and focus on helping the person live a good life around their pain) or cardiac or respiratory rehabilitation. They may also include social care to help a disabled parent look after their child, or support someone with chronic anxiety to leave their house.

Many of the services which allowed deinstitutionalisation last century have now been cut. People don't cease to be disabled just because the resources are no longer there to serve them. One good example is supported accommodation which is now widely only available for 3-5 years. All the rehabilitation in the world isn't going to make those with high and long-term support needs suddenly able to maintain a tenancy with minimal support at the end of 5 years.

Question: What things have the biggest influence on your mental health and influence your quality of life?

- housing
- provision of social care
- employment and job security
- money and debt management
- social and family relationships
- physical health
- connection to your community
- other please specify

¹² livinganddyingwell.org.uk/assisted-dying-bill-can-you-really-tell-if-someones-of-sound-and-settled-mind-for-suicide/

Question: What more can we do to improve the physical health of people living with mental health conditions?

This will support our ambition to reduce the gap in life expectancy between people with severe mental illness and the general population.

Question: How can we support sectors to work together to improve the quality of life of people living with mental health conditions?

We would be grateful for input relating to:

- a) Infants and their parents or primary caregivers
- b) Children and young people
- c) Working age adults
- d) Older adults
- e) Groups who face additional barriers to accessing support

As above, we first need to provide the services which make life worth living. It is tragic when people are pushed towards suicide because their quality of life without those services is so poor.

We also need to act to restrict activists (including but not limited to the aforementioned Philip Nitschke) encouraging suicide, and to think clearly about the messages our society gives about the worth of people who are disabled or elderly. It would not be seen as acceptable to describe the lives of any other groups as not worth living.

Question: What can we change at a system level to ensure that individuals with co-occurring mental health and drug and alcohol issues encounter 'no wrong door' in their access to all relevant treatment and support?

This includes people in contact with the criminal justice system.

Chapter 6: how can we all improve support for people in crisis?

Question: What can we do to improve the immediate help available to people in crisis?

We want to hear from people who have experienced a mental health crisis, to understand what help you need.

We also want to hear from those who work or have worked within services who support people experiencing a mental health crisis.

We are interested in ways to embed 'best practice' of multi-agency working, considering the role of the NHS, social work and social care, the voluntary and community sector, local government, education settings and the police.

Please consider:

- a) Children and young people
- b) Working age adults
- c) Older adults

We learn in the introduction to the consultation paper that "all local authorities have a suicide prevention plan in place which addresses key local risk factors" and "every area in England now has a 24 hours a day, 7 days a week mental health crisis service." Chapter six rightly states that "emergency mental health care or talking therapies are not the answer, or are only part of the picture; their most urgent needs are for support to resolve social factors that contribute to their crisis, such as problem debt, addiction, or housing. And some people may simply prefer to access support from a different sector, such as voluntary services."

Among those presenting in crisis are people who are terminally ill experiencing severe pain or other distressing symptoms which can only be dealt with through high-quality palliative care. Unlike the 24/7 mental health crisis services, whether palliative care is available out of hours is a lottery depending on the funding of local palliative care.

Taken together, we would argue that "key local risk factors" must include shortcomings in access to treatment for those who are terminally ill thanks to national or trust policies (postcode lotteries) and funding constraints.

Writing for Marie Curie in 2021, Dr Evie Papavasiliou said: "When accessing out-of-hours care, people are unlikely to receive care from someone who's familiar with them or has detailed information on their situation. Without this information, it can be very hard for out-of-hours professionals to differentiate between people whose condition could be reversible with hospital care and those who would be best cared for at home... Out-of-hours services are often busy and overstretched, and this is having a knock-on effect on the wellbeing of people at the end of life, and their loved ones... We need services which are reliably and rapidly available 24 hours a day, seven days a week – and are consistent across the UK – so that we can avoid some of these hospital admissions and everyone can access the care they need, when and where they need it... Reducing potentially avoidable hospital admissions near the end of life is also an opportunity to save on hospital spending and put this money into community-based services instead."¹³

Responding appropriately to a palliative care crisis can potentially fend off a mental health crisis. Much depends too on knowledge of one's options: chapter six states that "not everyone will reach out to the NHS when they or someone they know is in crisis. This may be because they do not believe that services will be available, because of the stigma associated with self-harm, suicide and seeking mental health support, or due to fear or mistrust of services. Sometimes this mistrust is driven by previous poor experiences or culturally inappropriate care." Much the same can be said of end-oflife care services; a great many people who express a wish to die to healthcare professionals are subsequently reassured when the full range of support options are laid out for them, but this depends on resourcing, access and public awareness.

Outside the group of the terminally ill, people whose mental health crisis is triggered by social causes will rightly want help that aims to resolve these. We need people allied to health and social care who can provide this support.

One of the classic situations which can trigger suicidality is benefit sanctions, leaving someone with no money at all for weeks to months. People with health problems which are not judged completely disabling are in the group most likely to experience sanctions (for example, for not managing to attend a course due to ill health). There needs to be a streamlined appeal system which can keep the supported person fed and housed in the interim. Another common trigger is disability benefits coming up for reassessment. People do not have confidence that their assessment will align to

¹³ mariecurie.org.uk/blog/palliative-emergency-admissions/313668

whether or not someone would be willing to employ them, and fear, hunger and debt if these benefits are removed. Their despair is unlikely to remit without the practical help they need.

We note the substantial references in Annex A to unemployment being "associated with increased stress, depression, anxiety and increased suicides" and there being "a clear relationship between debt and mental health." The financial effects of long-term physical ill-health can be catastrophic; a landmark 2019 report from Marie Curie titled "The Cost of Dying"¹⁴ recorded that:

- The total cost of living with a terminal illness in the UK can be between £12,000 and £16,000 per year
- More than 4 in 5 families living with advanced cancer face income loss as a result
- Many carers spend over 40 hours a week caregiving with impacts on their own work and income
- 43% of people caring for someone at the end of life say they struggle financially
- 60% of people living with some terminal illnesses rely on benefits as their main source of income
- Many families build up a 'debt legacy' to meet costs of living and care
- Disadvantaged families can spend as high as 98% of their income on the added costs brought on by terminal illness

In recent months, Canada has seen a spate of cases where individuals seek euthanasia/assisted suicide (MAID) not because of the illness which renders them eligible for state assistance in this regard, but because of the state's failure to assist them in living with dignity. Dr Kevin Yuill wrote¹⁵ of one: "Sophia (also not her real name), a 51-year-old Ontario woman, who suffered from... severe sensitivities to chemicals... was euthanised back in February, after she could not find affordable housing free of cigarette smoke and chemical cleaners. Four doctors wrote to federal government officials on her behalf, urging them to offer alternative accommodation. 'The government sees me as expendable trash, a complainer, useless and a pain in the ass', Sophia said in a video filmed eight days before her death."?

Question: How can we improve the support offer for people after they experience a mental health crisis?

We want to hear from people who have experienced a mental health crisis, to understand what help you need.

We also want to hear from those who work or have worked within services who support people experiencing a mental health crisis.

Please consider:

- a) Children and young people
- b) Working age adults
- c) Older adults
- d) Groups who face additional barriers to accessing support

We note chapter six's statement that "two-thirds of people who end their life by suicide are not in contact with NHS mental health services. Given the diverse potential reasons for a person's crisis,

¹⁴ mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2019/00962-cost-of-dying_financial-impactreport.pdf

¹⁵ <u>spiked-online.com/2022/05/06/in-canada-death-is-cheap/</u>

and variation in whether, when and how they will seek help, it is vital that different types of support are available. Many sectors have a role to play in identifying someone who may be in crisis and providing the care they need."

We agree with this and make further reference to the need for accompanying services (e.g. equal access to palliative care, regardless of location, age etc). We also refer back to Baroness Hollins on undiagnosed depression in terminally ill people: only 2 of the 238 people who died by assisted suicide in Oregon in 2021 were referred for psychiatric evaluation. The median length of doctor-patient relationship for that year was five weeks, with some knowing the doctor who cleared them for less than one week, so these were not decisions based on long-standing knowledge of the patients. Again, we assert that patients with physical ailments deserve full and considered assessments for mental ill-health.¹⁶

Among those with longer term disabilities, access to appropriate services to allow them to live well with their disabilities (physical or mental) is crucial. We agree with the statement in chapter 6: if someone's crisis is brought about by debt or a housing crisis then the help they need has to be able to support them to change this situation. (And so, those providing it need the resources to do this). This is every bit as true for the person with schizophrenia as the one with severe arthritis.

There's also a need for safe places where those experiencing acute suicidality can be supported safely until their distress, and acute suicidality, subside. This needs to be in addition to the practical help and services they need.

Question: What would enable local services to work together better to improve support for people during and after an experience of mental health crisis?

We would like you to consider the range of public services involved in crisis support, including the police and NHS services, as well as voluntary and community sector and businesses.

Next steps and implementation

Question: What do you think are the most important issues that a new, 10-year national mental health plan needs to address?

- wellbeing and health promotion
- prevention
- early intervention and service access \checkmark
- treatment quality and safety
- quality of life for those living with mental health conditions \checkmark
- crisis care and support
- stigma
- other please specify

Question: Please explain your choice.

Our choices reflect the need to avert mental health crises in people with terminal and chronic illnesses and disabilities by ensuring equal, fully-resourced access to support and treatment.

¹⁶ <u>oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf</u>

Regardless of the proportion of physical, mental and social needs in any one individual, they need to be supported to build a life they value, rather than being told that suicidality is appropriate for them.

Question: What 'values' or 'principles' should underpin the plan as a whole?

'Principles' and 'values' can help us to agree what the purpose of a plan should be, and what it should be seeking to achieve for people.

For example, the NHS is underpinned by the principle that access to the NHS is based on clinical need, not an individual's ability to pay.

Physical ill-health, especially terminal and chronic illnesses and disabilities, must never be seen as reason to assess suicidal ideation as a reasonable response. Healthcare professionals and partners in wider society must work not only to address the range of mental health factors which accompany such prognoses, but must also strive to change attitudes which devalue the lives of whole groups of people.

Question: How can we support local systems to develop and implement effective mental health plans for their local populations?

You might want to consider barriers local systems currently face, as well as enablers which would support more effective ways of working.

We need to give social and third sector services the resources they need to support people with longstanding or terminal illnesses. We need support that people can access before becoming suicidal and for this support to be advertised at key risk points, such as benefits reviews, sanctions or deteriorating health.

In terms of terminally ill people, hospices are at the heart of their communities and ideally placed to develop and implement mental health support plans for the terminally ill and their families, and those affected by bereavement.

Local plans are in place for new developments for hospices. Support from Government would help them achieve their targets.¹⁷

Question: How can we improve data collection and sharing to help plan, implement and monitor improvements to mental health and wellbeing?

¹⁷ martlets.org.uk/newhospice/