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Palliative and End-of-Life Care at the Deep End

Trauma-informed and inclusive approaches to palliative and end-of-life care for people experiencing marginalisation

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Churchill Fellow 2023

Palliative and End-of-Life Care at the Deep End

Trauma-informed and inclusive approaches to palliative care for people experiencing marginalisation

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Photograph depicts *Homeless Jesus*, a sculpture by Timothy P. Schmalz, situated outside the Cathedral of St John the Divine, Amsterdam Avenue, New York City, USA

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Dedication

"And some of us who have already begun to break the silence of the night have found that the calling to speak is often a vocation of agony, but we must speak. We must speak with all the humility that is appropriate to our limited vision, but we must speak."

- Dr Martin Luther King Jr.[1]

This work is dedicated to:

- all people who have been traumatised (and re-traumatised)
- all marginalised people
- all victims of inter-generational trauma as a result of historical oppression, colonisation, imperialism, and genocide
- all people experiencing systemic oppression, apartheid, torture, or genocide in the present day

This work would not have been possible if not for the generosity of the people experiencing marginalisation who I had the privilege to meet along my journey. My intention is to give attention and power to those who have been disempowered. I apologise if anything in this report does not live up to this intention, for any things which I get wrong, or any place where my tone is too paternalistic. This is a failing of, as Dr King would call it, my own limited vision. I am aware I still have much **unlearning** of my own to do, and I would appreciate you helping me to do better.

I hope this report makes some contribution to driving change that will benefit people experiencing marginalisation and take a small step towards a more inclusive tomorrow and better palliative care for all.

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Most of all I am thankful for the contribution of people experiencing **structural vulnerabilities** who I met during the course of my research, including those who are homeless or vulnerably housed, those who use drugs or are in prison, Indigenous people, people from other racialised minority groups and those living with HIV, and all others who experience or have experienced trauma and/or marginalisation. This work would not have been possible without the incredible assistance and generosity of spirit that you have shown – and for that, I thank you.

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Executive Summary

It is my privilege to present my report **Palliative and end-of-life care at the deep end**, representing the results of my Churchill Fellowship which explored overcoming the problem of **inequity** in palliative and end-of-life care access in the UK. This report is the culmination of international learning and discovery which has led to the development of ten recommendations for inclusive **trauma-informed** palliative care.

I focus in detail on the needs of people who are in prison and people experiencing homelessness (encompassing all forms of homelessness and being vulnerably housed), as these are underserved communities with complex needs for whom palliative care access is a growing public health concern. This report is written to be accessible to and, I hope, useful to:

- all people involved in enhancing or supporting the quality of life of people who are experiencing homelessness or are in prison (across all sectors)
- all people involved in providing palliative and end-of-life care (which will be relevant to the majority of people working in healthcare, at least some of the time)
- all people working in **specialist palliative care**
- everyone interested in the rights and welfare of vulnerable people in our society affected by marginalisation

The problem of inequity in palliative care - and how to fix it

Palliative care is a force for good. I use the term palliative care as a broad concept capturing all support and care which enhances the quality of life of people with life-threatening conditions, including end-of-life care, regardless of where these actions and services are provided and by whom (whether healthcare professionals or not). Palliative care provides a significant benefit to the lives of people who have access to it. The problem with palliative care lies in **inequity** of access, as the most disadvantaged members of our society – including racialised minorities, people living in social deprivation or who are homeless, and people in prison – often do not have adequate access to high-quality palliative care when they need it.

Although people providing palliative care may try to act with **equality** – being willing to offer the same care to everyone – there are many for whom mainstream ways of 'doing palliative care' are not working. For those who are homeless, barriers to palliative care access include lack of healthcare-seeking behaviour, lack of places for care, and lack recognition of when a homeless person may be dying or require palliative care. For people who are in prison, barriers to palliative care access include lack of training and availability for prison staff to provide care, inconsistency in **specialist palliative care** input and access to prisons, and the physical prison environment being unsuitable for the care of frail and unwell patients.

These barriers exist despite these marginalised groups having significant needs. For example, people experiencing homelessness have a rate of death four times higher and a far-reduced life expectancy compared to the general population (e.g. for those experiencing homelessness in Scotland the life expectancy is 39 years old for women and 43 years old for men).[2] People in prison undergo premature ageing and the vast majority have at least one major health problem.[3]

We can therefore consider homelessness and imprisonment themselves as being life-threatening conditions for which palliative care should be available.

Palliative care should be the business of all those working with people from these marginalised groups, including those working and volunteering in social services, the homeless and the prison sectors. To improve palliative care access for people experiencing marginalisation, we must strive not just for **equality** but for **equity**: altering and adapting our palliative care approaches to meet the unique needs of patients.

Equity through trauma-informed approaches

Adopting **trauma-informed approaches** is crucial to achieving **equity** in palliative care. **Traumatic experiences** lead to traumatisation: lasting neuro-biological changes which affect behaviour and predispose survivors to multiple negative consequences including chronic physical and mental illnesses, higher rates of substance use, reduced life opportunities, and risk of early death.[4] People experiencing marginalisation have often had significant trauma in their lives, meaning life-threatening illness and encounters with healthcare professionals pose a risk of traumatisation. **Retraumatisation** may occur when something in a present experience is reminiscent of a past threatening experience, causing the affected person to become traumatised again.[5]

To achieve **equitable** care for people experiencing marginalisation, we therefore take **trauma-informed approaches.** This involves integrating into our practice the key principles:[6]

- safety
- trustworthiness and transparency
- peer support
- collaboration and mutuality
- empowerment, voice, and choice
- sensitivity to cultural, historical, and gender Issues

There is no one-size-fits-all approach to being **trauma-informed**, and we must be guided by what our patients tell us they need.

This Fellowship research project

As a UK-based palliative care physician, educator, and researcher, I devised this Churchill Fellowship research project to find ways to make UK palliative care more **equitable** and inclusive. I aimed to develop recommendations for inclusive approaches to palliative care for people experiencing marginalisation in the UK through learning from care delivery elsewhere in the world.

To meet this aim, I conducted a six-week exploratory travelling fellowship to learn from centres of care in the USA and Canada. At these sites I observed practice, gained an understanding of the structure and history of these initiatives, and learned about their philosophies of care. This comprised exploratory visits to:

- Commonwealth Care Alliance, Massachusetts, USA
- Center for Urban Community Services and Janian Medical Care, New York City, USA
- Humane Prison Hospice Project, California, USA

- Equity in Palliative Approaches to Care (ePAC) and Palliative Outreach Resource Team (PORT), Victoria, Canada
- Ottawa Inner City Health Inc. including the Diane Morrison Hospice, Ottawa, Canada
- Palliative Education and Care for the Homeless (PEACH), Toronto, Canada

Recommendations for inclusive trauma-informed palliative care

These recommendations are not prescriptive and are provided at the level of general principles. I encourage each individual and/or organisation to consider how some or all these recommendations may be integrated into their practice, adapting the ideas to the local context and the needs of the people they serve. My ten recommendations for inclusive **trauma-informed** palliative care are as follows:

1. **Early contact and persistency – to meet people where they are**
   Those experiencing marginalisation may not engage with healthcare professionals in the way we usually expect from other patients. Inclusive approaches should be pro-active, have low barriers to access, initiate contact early, be persistent, and accept people where they are – literally and figuratively.
2. **Peer-to-peer care and support**
   Palliative care approaches for people experiencing marginalisation should include and be guided by people from within the same marginalised community. Peer-to-peer support or peer-to-peer care workers can increase patients' comfort and trust in palliative care and facilitate effective advocacy for people experiencing marginalisation.
3. **Prioritise housing as healthcare**
   Homelessness leads to worse health outcomes and increased mortality. Our holistic approach to improving quality of life should acknowledge housing as healthcare. Providing housing is therefore a component of palliative care which can be achieved through adopting the principle of **Housing First**. I pose the question of whether our systems can adapt to allow us to ***prescribe*** **housing** as a palliative care intervention.
4. **Adopt a harm reduction approach to substance use**
   Systems and settings which require abstinence from alcohol and drug use may alienate patients and result in difficulty maintaining a trusting, therapeutic relationship. In contrast, a non-judgemental harm reduction approach can help to increase patient access to and acceptance of palliative care, while reducing harms associated with substance use.
5. **Embed mental health care**
   Many people experiencing marginalisation have experienced or are experiencing trauma, and a significant proportion will also have **Severe and Persistent Mental Illness**. Inclusive approaches to palliative care should facilitate and allow patients to access the mental health care they need, and there should be good working relationships between palliative care and mental health care teams.
6. **Utilise resources wisely**
   Trauma-informed inclusive palliative care approaches require substantial resources. By building good relationships with colleagues across organisations and settings, we can strategically utilise or repurpose existing resources to reach patients more effectively, while reducing inefficiencies and waste, and streamlining the patient experience.

7. **Cultivate a place of peace**
   Providing a peaceful physical environment can give people time and space to rest from the difficulties and worries of life. A place of peace should be one of reduced power disparities between patients and professionals. Whether or not we are able to offer a discrete physical place of peace, we should strive in our work to create an environment and atmosphere of peace where patients, their loved ones, and workers can feel safe.
8. **Accept dying is different for every person**
   It can be difficult to recognise dying in a person experiencing marginalisation, and it is often people who know the patient well who are best placed to identify the subtle changes indicating that their condition is changing. Inclusive palliative care must involve responding to concerns that a person from a marginalised community may be dying, no matter who the concerns are raised by, even if the concerns seem vague. Furthermore, we should be aware people's wants for and behaviour during their dying process are as diverse as people's lives. We should accept that what brings comfort to a dying person experiencing marginalisation may not fit with more mainstream ideas of the dying person.
9. **Acknowledge and share grief**
   Those experiencing marginalisation may experience multiple, often traumatic, losses throughout their life, yet their grief may not be seen as valid by wider society: they are at risk of **disenfranchised grief**. **Trauma-informed** bereavement services should be adaptable and accessible to the differing needs of people from marginalised communities. Furthermore, people working in healthcare including palliative care are often expected to suppress sadness and distress over the deaths of patients, while people who experience marginalisation throughout their life can feel that others do not see their lives as important. Open acknowledgement of the grief and the legacy left behind is a way to express the value of the person's life, to reduce the **vicarious trauma** experienced by workers, and to support one another through bereavement and grief.
10. **Unlearning and change in the professional team and within organisations**
    People and organisations working in palliative care may not find it easy to implement these recommendations and to accept doing things differently. The way forward involves **unlearning** established norms and ways of thinking including changing the roles and expectations of staff, seeing people experiencing marginalisation as co-workers and colleagues, and changing our attitudes towards patients' use of alcohol and drugs.

The future

These ten recommendations aim to promote inclusive palliative care in the UK. The recommendations focus on people in prison and those experiencing homelessness, but there is a large overlap between these groups and other **structurally vulnerable** groups (especially people who use drugs and those with **Severe and Persistent Mental Illness(es)**). I hope these recommendations can be useful when developing inclusive approaches for any or all people experiencing marginalisation.

Making UK palliative care more inclusive is challenging – but it is also exciting. I am aware these recommendations are not easy to adopt. Many of the recommendations go against the grain of established ways of working in the UK. You may even find some of the ideas in this report shocking. However, it is our responsibility to find new ways of doing things. Given the huge – and growing – unmet palliative care needs of people living and dying at society's margins, we must do

better. I hope these recommendations will trigger reflection, conversations, and new ideas, so we can all consider how we tackle the vital problem of **inequity** in palliative care.

Developing more inclusive palliative care may be resource-intensive, but I believe this goal is achievable through greater collaboration and communication between different professionals and organisations providing care and support for people experiencing marginalisation. Awareness and appreciation between services of each other's role and scope is crucial, including awareness that everyone has the right to palliative care – including referral to **specialist palliative care** services – regardless of circumstances. I believe by working together we can develop new to create better outcomes for our patients.

I would be delighted to hear from you about your work with people experiencing marginalisation, about how you are thinking of taking on the recommendations made in this report (or whether you think they should be modified), and of potential ways of collaborating. I hope we can be inspired by the revolutionary spirit of palliative care, which was originally born of a desire to break away from the old ways of doing things to help those in need. Through this revolutionary spirit, I hope to see the start of conversations and innovation, ultimately leading to change. I look forward to working together to bring excellent palliative care to everyone who needs it!

Shaun Peter Qureshi

Palliative care physician, researcher and educator

Churchill Fellow 2023

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Introduction

This report – **Palliative and End-of-Life Care at the Deep End** – presents recommendations for overcoming the problem of **inequity** in palliative and end-of-life care access and provision in the UK. This report is the culmination of my international learning and discovery, as a Churchill Fellow, from centres which provide inclusive holistic palliative care in the USA and Canada. Reflecting on how the practice I observed in North America could apply to our UK context led me to develop ten recommendations for inclusive **trauma-informed** palliative care for people experiencing marginalisation.

The report focuses on the needs of people from two specific marginalised groups: people in prison and people experiencing homelessness (encompassing all forms of homelessness and being vulnerably housed). These are under-served communities with complex needs for whom palliative care access is a growing public health concern in the UK. However, there is a large overlap between **structurally vulnerable** groups, and this report can hopefully be useful for advancing inclusive palliative care for all marginalised people.

I hope it will be of use to everyone working with people experiencing marginalisation across all sectors, everyone working in healthcare across any setting, including **specialist palliative care**, and everyone interested in the rights and welfare of the most marginalised. In writing this report, I have aimed to make it accessible to people with no existing knowledge of **trauma-informed approaches**, palliative care, or care of people experiencing marginalisation, while at the same time aiming to be of use to those with more experience or expertise in these areas.

I am aware there are many terms and ideas to be found in this report, some or all of which might be new to the reader, therefore the report begins with a **Background section** which introduces the salient ideas built upon in this report (and there is also a **Glossary** to check the meanings of terms highlighted in green whenever needed). The **Background section** starts with explaining palliative care, including the importance of addressing the problem of **inequity** in palliative care. I introduce the concept of **structural vulnerability**, i.e. being made vulnerable to worse outcomes in life because of power imbalances in social, economic, political and cultural systems.[7] The section then provides an overview of those experiencing homelessness and those in prison, including how **structural vulnerabilities** affecting these groups provide challenges for accessing palliative care when they need it. The **Background section** presents important information on trauma to consider when caring for people experiencing marginalisation, including elaborating on the purpose and principles of **trauma-informed approaches**.

The report then moves on to the **Research process section** in which I articulate the research aims, describe the methods I undertook in this Fellowship research, and I provide some information about myself and my motivations for this research. The **Recommendations section** then presents the results of this work: ten recommendations for inclusive **trauma-informed** palliative care for people experiencing marginalisation. These cover a range of ideas and approaches relevant to palliative care and marginalised groups, from peer-to-peer care to mental health care to the importance of support through bereavement and grief. Social justice is central, reflected, for example, in highlighting the importance of housing and harm reduction approaches to drug and alcohol use.

My report recommendations are not intended to be prescriptive, but instead are written at the level of general principles and attitudes. Every individual, team and organisation reading it should consider how some or all of these recommendations may fit with your local context and might be adapted to help support and care for the people you serve. Forging new ways to practise and provide palliative care will be challenging, but it is also exciting.

I am looking forward to hearing your response to my report, to learn from you about your work with people experiencing marginalisation, and to potentially working together – please reach out using my contact details in **The future: working together section**. It is my strong hope this report can trigger reflection, conversations and new ideas, so we can all work together to tackle the problem of **inequity** in palliative care.

Note that terms in **green** in this report can be found in the **Glossary** with an accompanying definition – so, as you read this report, check the **Glossary** whenever you need to

Background

Palliative Care

"Palliative care teaches us what good care looks like. The real problem we are left with is how to move a palliative approach to care upstream" [1]

Palliative care has a problem

I believe palliative care is a force for good. So much so, I have dedicated my career to helping people who need it. I do my best to contribute through my clinical patient care as a doctor, as well as through other activities like research and service improvement.

Nevertheless, I believe palliative care has a problem. Palliative care makes a positive change for those lucky enough to receive it, but the problem lies in the **inequity** of its distribution. Not everyone who needs palliative care gets it. It is this central problem that is the crux of this report which I aim to address. In this section, I expand on what palliative care is, how it helps people, and why **inequity** in palliative care is an important problem we need to solve together.

What is palliative care?

Palliative care is a frequently used term in healthcare and wider society. However, people often don't have a clear idea about exactly what it means.

At different times, **palliative care** seems to mean different things. Such as:[9]

- types of medical treatments
- the absence of types of medical treatments
- a category of nursing or social care
- a type of clinical setting
- the name for a medical specialty
- a type of clinical professional team
- a way to identify certain people or patients needing care
- a type of need
- an attitude
- a responsibility held by all healthcare professionals
- a responsibility held by all people interacting with the public and distributed throughout society
- a right
- and many more ideas!

Given this variety, it is not surprising the concept of palliative care can cause some confusion – including among healthcare professionals themselves. The purpose of this report is not to produce a single definition of palliative care. However, I believe it is necessary to spend time

exploring the concept, first principles, and landscape of palliative care to understand where the problems lie – and why this report is needed.

My understanding of palliative care is as a holistic ***approach to care*** which promotes quality of life for those with serious progressive illness, and their loved ones. It is a life-enhancing approach which helps people live their life to the full in their individual circumstances. My belief about palliative care corresponds with the following from Dame Cicely Saunders, founder of the modern hospice movement:[10]

> **"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."[10]**

Another cause of confusion can be the relationship between palliative care and care for people who are reaching the very end-of-life. Are palliative care and end-of-life care the same thing? Or different?

I believe palliative care and end-of-life care are not the same, but they are connected and they overlap. Palliative care is important for those with all serious, **life-threatening conditions**, and may be delivered at every stage of the illness, from the point of diagnosis. In other words, palliative care is not only for people who we know are definitely going to die and it is not only for people who are imminently dying. End-of-life care is when we provide palliative care for people who we know are going to die soon.

Palliative care may be different from other forms of healthcare, which tend to focus on treating underlying illnesses, because palliative care focuses instead on enhancing quality of life. However, for many, palliative care can be delivered alongside other treatments that are life-prolonging or to treat an underlying disease. Palliative care can also be delivered at later stages, when no more life-prolonging treatment may be possible or if someone decides they want to focus solely on comfort and stop life-prolonging treatment. Therefore, palliative care includes end-of-life care, but is wider than only this, as shown in the diagram below:

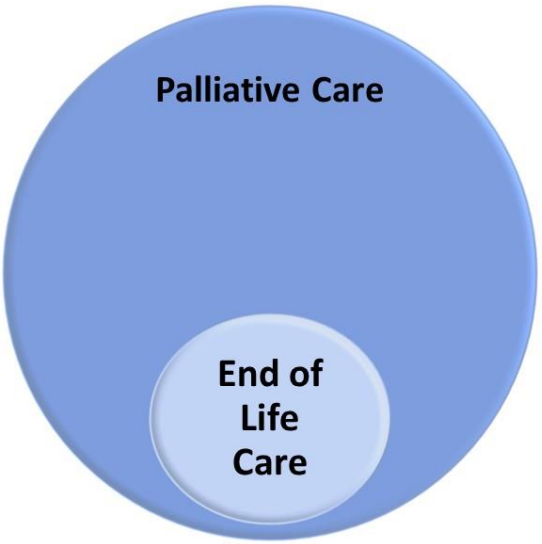


Diagram showing palliative care includes end-of-life care, but palliative care is wider than only this[11]

No two people are the same, nor do they have the same needs when experiencing a life-threatening illness. The way a person experiences palliative care will vary depending on their individual circumstances. Examples of this approach to care, which we call palliative care, can include:[11.]

- holistic assessment of a person's needs
- providing practical advice for the person and their carers, including signposting to relevant services or co-ordination with professionals involved in the care of the patient
- helping to control symptoms like pain, nausea, anxiety, and shortness of breath, including using medication when needed
- helping people to address emotional or spiritual challenges and come to terms with their life-threatening condition
- discussion of what matters most to the person with a life-threatening illness, including helping them to make decisions about how and where they want to be cared for, in a way which aligns with their wishes and values

These are just some examples. It is not possible to provide a definitive list of what palliative care can encompass. Ultimately, I believe we should be motivated by the principle of listening to our patients when they tell us what they are experiencing and what matters to them. We must remember the words of Margo McCaffery, pioneer in care of people with pain, when she said, "Pain is whatever the experiencing person says it is, existing whenever he says it does".[12]

"Pain is what the patient says it is"

In palliative care, our goal is to reduce the suffering and enhance the quality of life of our patients. Whether the person's pain be physical, social, psychological, spiritual – or a combination of these – we should let our patients tell us what their pain is and be guided to help them on an individual basis.

Who provides palliative care?

Some of the confusion surrounding palliative care relates to questions over when it starts, who is responsible, and who provides it. In the UK, palliative care is often seen as two different entities – **generalist palliative care** and **specialist palliative care**:[13]

- **Generalist palliative care** is a term for palliative care which can be provided by all healthcare professionals, in every healthcare setting, whenever a person needs it. This may be provided across the health service, by healthcare professionals including general practitioners, district nurses, nursing home staff, home care staff, hospital doctors and nurses, physiotherapists, occupational therapists, and social workers. The National Health Service in the UK can provide aspects of **generalist palliative care** without financial charge to the patient.
- **Specialist palliative care** relates to care provided by professional individuals or teams branded with the defined role of palliative care. **Specialist palliative care** is often based from hospices, but can be provided for people who are at home, in-patients in hospital, in-patients at a hospice unit, visitors at day units, residents of care homes, or people who move between these settings at different times of their life. Examples of healthcare professionals involved in delivering specialist palliative care include: doctors who specialise in palliative medicine, clinical nurse specialists, specialist physiotherapists and occupational therapists, counsellors, chaplains, and nurses who work in a hospice. **Specialist palliative care** is available free of charge to the patient in the UK, however in many cases it is provided by charitable organisations which are largely funded through charitable donations.

In this report, I argue for more expansive ideas about palliative care. We are motivated to reduce the physical, social, psychological, or spiritual pain for those who have life-threatening conditions, and to consider the person as a whole. I believe palliative care is not owned by **specialist palliative care** services. Nor is palliative care limited to the realm of healthcare. **Whenever someone is providing support or care to people in a life-threatening condition to enhance their quality of life –from support to find stable housing, to food, to spiritual care and support, or just providing someone to talk to – then palliative care is happening.**

The recommendations I make it this report are intended for everyone involved in **specialist *and* generalist palliative care**, which encompasses nearly everyone working in healthcare whenever they encounter a person with a life-threatening illness. I go further and say this report is intended for ***everyone*** working with people experiencing marginalisation. The support and care you give to people are important parts of the spectrum of palliative care.

So, what are the problems with palliative care?

The above explanation of UK palliative care and its provision sets out a positive impression. Certainly, palliative care is doing good for the people it reaches. However, I believe it is too limited in its provision. To explain, it is helpful to briefly look at a historical perspective on palliative care.

The ground-breaking history of palliative care

Palliative care was born in the 20th Century out of a social movement concerned with how the dying were neglected in society. Dying people were hidden from mainstream society, in hospitals and away from their communities. In response, the modern hospice movement was born. This new movement aimed:[14]

- to prevent and relieve suffering at the end-of-life
- for the dying person to be told the truth about their condition
- for the dying person to be given agency to make their own end-of-life decisions
- to reduce the power imbalance between the patient and the with the doctor
- for dying to be less 'medicalised' by bringing an open awareness of death, and allowing the dying person to stay connected to the community in which they lived

The hospice movement led to the establishment of 20th century modern-day hospices, developed to provide a place where the needs of dying patients were met in a different context from other available healthcare: open communication and unconditional care.[15] The modern hospice movement led to the recognition and development of palliative care as a concept: the approach to care which encompasses the values of the hospice movement. Palliative care represented a shift in attitudes compared to mainstream medicine. At the time of its emergence, palliative care was a revolutionary approach, inspired to champion the autonomy and welfare of the most vulnerable people in society.[16]

Losing the radical nature of palliative care

Despite its origins, some critics have argued palliative care has lost its revolutionary nature and the original goals of palliative care have not been reached. Palliative care was born from a movement aiming for death to be less medicalised: for dying people no longer to be hidden in institutions. Some examples of where it may be failing to meet its original values include:[17,18]

- in high-income countries, death still mainly occurs in institutions, hidden from mainstream society in hospitals, hospices, or care homes
- medical decision-making is still prioritised in a person's dying process
- palliative care has sought legitimacy by becoming increasingly aligned with the mainstream systems it originally sought to break away from

Critics argue that palliative care has become increasingly influenced by the **medicalised** model, losing its original character and values. Some say palliative care has becoming increasingly restricted and inflexible due to bureaucratisation and regulation.[19]

Inequity in palliative and end-of-life care

The World Health Organization recognises palliative care as a right under the human right to health.[20] Similarly, many governments state everyone has the right to high quality palliative and end of life care.[e.g. 21] So ***everyone*** who needs palliative care should receive it. Unfortunately, this

goal is not currently being reached. In the United Kingdom up to an estimated 25% of people who need palliative and end-of-life care are not able to access it.[22]

People with certain demographic characteristics, including minority groups and those at the greatest socioeconomic disadvantage, are least likely to receive high-quality end-of-life care.[23,24] Hospice UK, a national charity for hospice and end of life care, identified groups of people in the UK who are not being provided with equitable access to palliative and end-of-life care in the United Kingdom, including:[22]

- people from racialised minority communities
- people from sexual or gender minorities
- people living in poverty or deprivation
- people living with intellectual disabilities
- people experiencing homelessness
- people who are in prison

I believe it is worth considering whether palliative care truly lives up to its revolutionary purpose of breaking away from our mainstream systems and empowering vulnerable individuals. It appears to me that the people most likely to benefit from palliative care in the UK are those most likely to already experience privilege in society. Correspondingly, it is people who are already marginalised throughout their lives that do not have **equitable** access to palliative and end-of-life care at the end of life.

Fixing palliative care

Palliative care is a human right. Everyone diagnosed with a life-threatening illness should have access to it. This includes physical aspects of care including access to pain relief and humane treatment – but furthermore, everyone should be able to benefit from the full spectrum of palliative care: having what matters most to them be valued at the end-of-life. In this report, I hope to go some way to explore the issues of inadequate access to palliative and end-of-life care and make recommendations about how these problems may be fixed.

I understand professionals and organisations providing palliative care are unlikely to feel they are intentionally preventing palliative care access to people who are marginalised. Many will explicitly state they offer their care equally to everyone. To understand why this current approach of **equality** is not enough for people experiencing marginalisation, it is helpful to consider the difference between **equality** and **equity**.

Equality

Everyone gets access to the same, regardless of whether it is right for them

Equity

Everyone gets access to what they need (taking into account individual barriers, circumstances and conditions)[24]

However, there is no "one-size-fits-all" approach suitable for all. In fact, the conventional approach to palliative care provision is one adapted to suit people who are from majority groups and not experiencing marginalisation. This often does not work for minority groups or those experiencing marginalisation.

By thinking about how palliative care can be more dynamic and adaptive we can start to make access and provision of high-quality palliative and end-of-life care more **equitable**. To do this, I believe we should resume the revolutionary and "outside-the-mainstream" thinking that palliative care had in its origins. It is time to think about new ways of doing things to meet our goal: palliative and end-of-life care for everyone who needs it.

I do not pretend this report can single-handedly revolutionise the entire field of palliative care. **Equity** for all marginalised groups is important, but for the purposes of this report I focus in detail on two groups: those experiencing homelessness and those in prison. In the next sections, I go into more detail about marginalisation and **inequitable** access to palliative care for these groups.

Structural vulnerability

This report focuses on enhancing **equity** across palliative care. In the previous section, I discussed that access to palliative care is a human right, but not everyone is able to easily access palliative care when they need it. The people who experience the greatest challenges in accessing palliative care are often those who generally already experience the greatest disadvantage in life and have the least power in society. To think about why some tend to have worse outcomes and inequitable access, it is helpful to consider the concept of **structural vulnerability**.

The term **structural vulnerability** can be used to help understand how some people are made vulnerable to worse outcomes in life because of power imbalances reflected in social, economic, political, and cultural systems. These imbalances result in social hierarchies, with those at the bottom of the hierarchy being the most **structurally vulnerable**. This leads to those who are most **structurally vulnerable** people having:[7,8,26]

- the least choices and opportunities in life
- the least access to healthcare
- the greatest risk of harm
- the greatest risk of neglect and abuse
- the poorest health including chronic illnesses and premature death

The emphasis on **structural** vulnerability acknowledges that no person is born less worthy of having a good quality and length of life, but that problems are caused by the **structures** in our societies which have contributed to these negative outcomes. Thinking in this way should help us be conscious of who is disadvantaged and made vulnerable in our society.[7]

Structural vulnerability: A type of vulnerability stemming from social hierarchies causing reduced autonomy, fewer opportunities, increased risks as well as negative health impacts.[7]

Examples of **structural vulnerabilities** include living in poverty, homelessness or being a refugee or asylum seeker. The factors which make someone **structurally vulnerable** may be the result of systems of oppression including racism, colonialism, sexism, or classism. **Structural vulnerabilities** are not static, e.g. a person may become more or less vulnerable at different times in their life. There is a very large degree of intersection between groups, for example overlap between people experiencing homelessness and poverty, racism, and criminalisation.[26]

When a person nears the end of their life, their vulnerability and need for care increases. For those already **structurally vulnerable**, the approach to the end-of-life renders them even more so. People from these marginalised groups may have unique end-of-life needs not met by mainstream palliative care. Despite this, people who are **structurally vulnerable** often experience challenges in getting adequate access to palliative care.[26]

This report focuses on the needs of two **structurally vulnerable** groups: people who are homeless and people who are in prison. I am aware people in these groups are not mutually exclusive, and there is a large overlap with other sources of **structural vulnerability**. For example, in Scotland, out of three 'core' forms of severe and multiple disadvantage (homelessness, substance dependency, and involvement in the criminal justice system): 156,700 people experience one of these forms of disadvantage per year; 28,800 experience two of these per year; 5.700 experience all three forms per year.[27]

To keep this report focused and within scope, I will mainly focus on those who are homeless and those who are in prison – or people affected by both these **structural vulnerabilities** – with the hope this report can convey learning useful for the care of all people experiencing **structural vulnerability**. In the next sections, I expand on the need for improved palliative care for people experiencing homelessness and people in prison.

Homelessness

What is homelessness?

Many different but similar definitions of **homelessness** exist but generally we can say being homeless means not having suitable accommodation in which to live. Homelessness can take different forms including:[28]

- rough sleeping
- living in a hostel or B&B without a stable base
- staying in a shelter or temporary accommodation
- couch surfing
- being at risk of imminently lose a main night-time residence
- being an unaccompanied child or young person
- fleeing or attempting to flee domestic violence, sexual abuse, stalking, or other dangerous or life-threatening conditions

The most visible forms include rough sleeping and staying in a shelter and are typically ***late*** presentations of homelessness. In other words, homelessness is a much more common problem in our society than those of us who are stably housed generally see in our day-to-day lives.

Those who are homeless are socially excluded, with the deepest social exclusion affecting those affected by other forms of **structural vulnerability** also. The term **multiple exclusion homelessness** can be used to describe the deep social exclusion of those affected by homelessness plus institutional care (e.g. prison), substance use, or involvement in street culture activities (e.g. begging and street drinking). **Multiple exclusion homelessness** is more likely is more likely in those who experienced **trauma** as a child.[29] See Page 40 for further discussion on **trauma**.

Health and homelessness

Health outcomes for those experiencing homelessness are much worse than for those who are stably housed. Among people experiencing homelessness in the United Kingdom:[2]

- 80% have at least one physical health problem
- 20% have at least three health problems
- 45% have a mental health problem diagnosed
- 80% have self-reported mental health issues

Furthermore, compared to the general population, people experiencing homeless in the United Kingdom:[2,30,31]

- are at greater risk of infections including hepatitis, HIV, and tuberculosis
- are 29 times more likely to have hepatitis
- are 12 times more likely to have epilepsy
- are 6 times more likely to have heart disease
- are 4 times more likely to have cancer

- are at a greater risk of suicide
- are at a greater risk of unintentional injury
- are at a greater risk of poisoning and drug overdose
- have death rates 4 times higher

Many people experiencing homelessness often have a physical health condition, mental health issues and live with drug or alcohol dependency. The combined impact of physical illness, mental illness, and substance use is known as **tri-morbidity**. Despite the disproportionate amount of social hardship and medical illness, people who are homeless experience problems accessing healthcare.[2]

Homelessness is a life-limiting condition

In high-income countries, many illnesses and premature deaths are preventable through the provision of stable housing and reliable access to proper health care. However, people experiencing homelessness unfortunately do not benefit from stable housing and reliable healthcare access, leading to far worse health outcomes described above.[32]

The result is that people experiencing homelessness have a far lower life expectancy than the general population, and that homelessness itself is a risk factor for early death. In Scotland, for example, more than 200 people die each year while homeless. The average age of death for people experiencing homelessness in Scotland is 39 years old for women and 43 years old for men.[2] Scotland has the highest rate of homeless deaths per million population in the UK, almost three times that of England and more than three times that of Wales.[33] These findings tells us that homelessness is itself a life-threatening and life-limiting condition.

Homelessness is a life-limiting condition

Challenges for palliative care when a person is homeless

Given the life-limiting nature of homelessness and the impacts of homelessness on quality of life, palliative care should be provided to people experiencing homelessness and ill health. However, there are several barriers in palliative care, including **specialist palliative care**, being offered to or accessed by people experiencing homelessness. Below, I highlight some of these many barriers.

Identifying people with palliative care needs

For those experiencing homelessness, identification of palliative care needs is challenged due to these people often having multiple, complex health issues. They may not behave the way professionals usually expect, which may be influenced by complex **trauma**. Also, death and dying may not be considered an imminent possibility due to a homeless person's young age. In reality, we should be aware of the risk of death and dying among young people who are homeless, due to their risk of dying at a much younger age compared to the general population.

A further challenge lies in lack of training to recognise palliative care needs among the professionals who spend most time with people experiencing homelessness. Much of the care for homeless people is provided by workers outside formal medical systems (e.g., outreach and housing workers). These workers often have limited health or palliative care experience or training. Without specific training, they are potentially unable to recognise the significance of a person's illness or associate the person's symptoms with the need for palliative care.[26]

Moreover, a large proportion of the practical and emotional support provided for people experiencing homelessness is undertaken by specialist third sector homelessness organisations and temporary accommodation providers which do not have direct links with **specialist palliative care** providers.[2]

Additionally, it can be challenging – for everyone, healthcare professionals included – to accurately predict when the health of a person experiencing homelessness might deteriorate. To explain this more clearly, it is helpful to consider different potential typical **illness trajectories**, i.e. the course different illnesses might take over time in different categories of disease. Diagrams below show typical patterns for sudden death, steady decline, roller coaster decline, and slow decline.[34]

Diagram below showing trajectory of sudden death

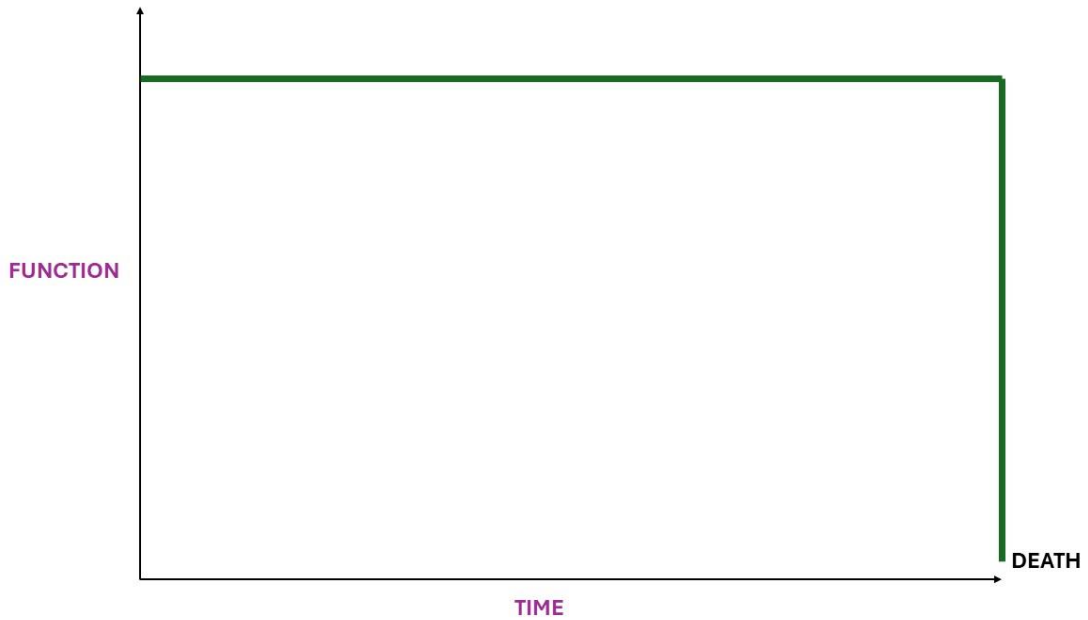


Diagram below showing trajectory of steady decline

Diagram below showing trajectory of roller coaster decline

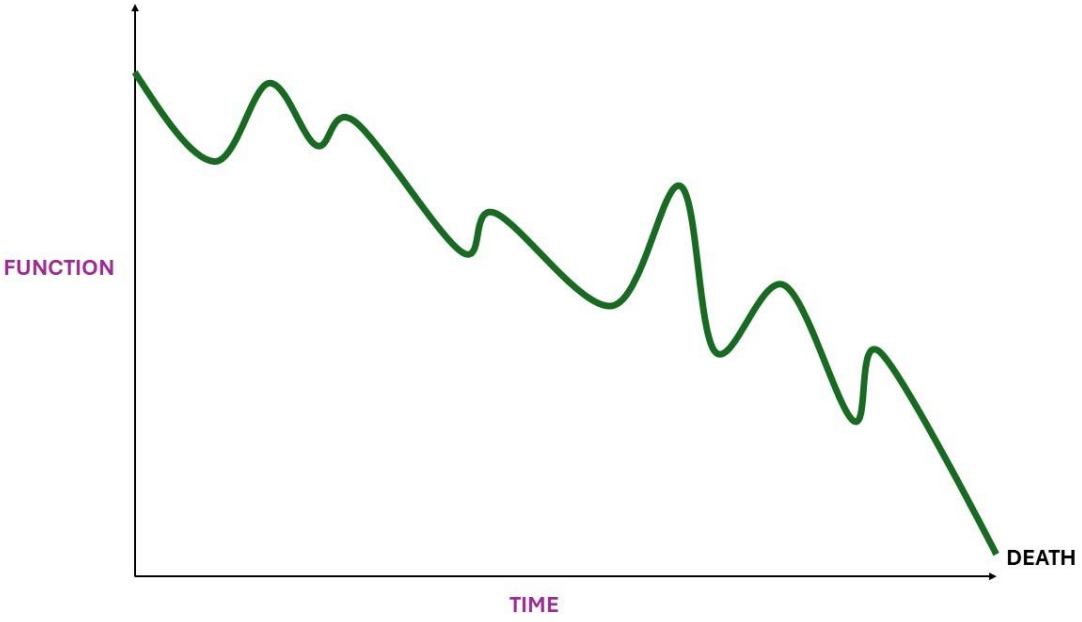
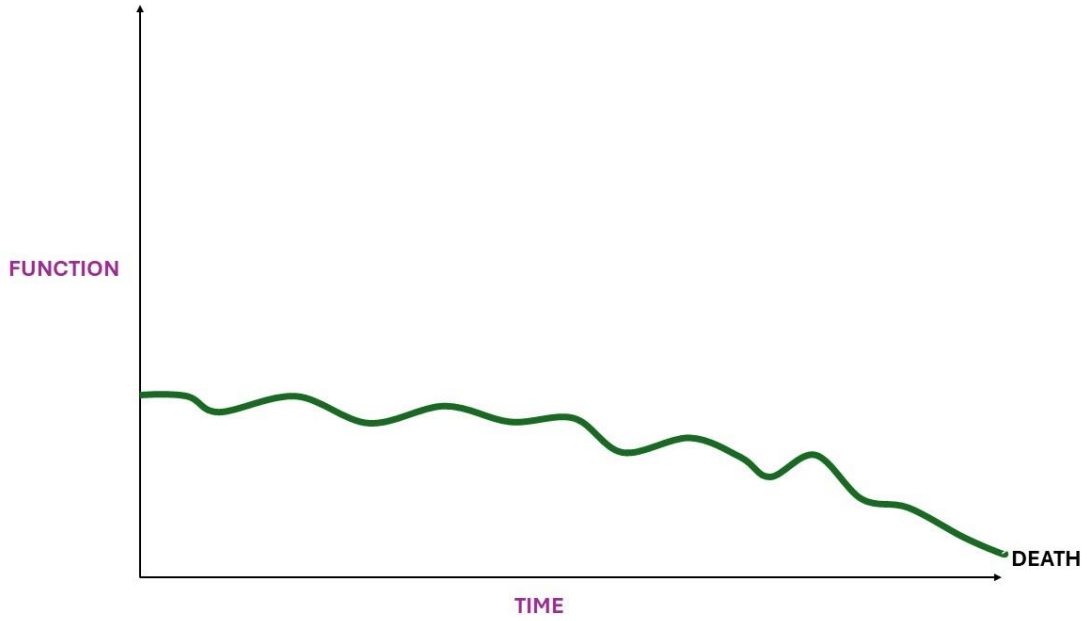


Diagram below showing trajectory of slow decline



Diagrams showing illness trajectories adapted from Equity in Palliative Approaches to Care. Palliative Care Is... A Collective Response to Death, Dying, and Grief in The Inner City. 2023. University of Victoria.[33]

Specialist palliative care services were originally designed to meet the needs of people dying from cancer, experiencing a steady decline in health leading up to death. This steady decline is often predictable, perhaps making it easier to identify when patients who have cancer need palliative care.

In contrast, people experiencing homelessness may be affected by life-limiting illnesses which cause them to experience a **trajectory** of a roller coaster decline, for reasons such as organ failure affecting the heart, lungs, or liver. They are also at risk of sudden death from threats such as violence and poisoning. These difficulties with predicting how close a person is to the end of their life often present a barrier to supporting people experiencing homelessness with timely palliative care.[34]

Organisation of care services

In the UK, **specialist palliative care** services generally rely on referral into the service from another professional. Without such a referral, palliative care services will probably not be aware of a patient and be able to offer care input. At present, there are too few people experiencing homelessness being referred to **specialist palliative care**. As a result, palliative care and other health care services may be utilised late on, only at times of crisis, when the condition of the person experiencing homelessness is already at an advanced stage. In many other cases, people experiencing homelessness are not referred at all, with many falling between the cracks.[2]

Further, we must reflect on whether **specialist palliative care** services are truly designed with the needs of all in mind, and whether palliative care professionals are equipped to care for people experiencing homelessness. Most who do access **specialist palliative care** tend to be from comfortable socio-economic backgrounds or come from dominant (non-marginalised) social groups, or have strong family and community connections and are stably housed. It appears, therefore, that the needs of people experiencing homelessness are neglected by the dominant ways that **specialist palliative care** is organised and modelled.[24,26]

Professional risk assessment

Services may be reluctant or decline to provide care for people experiencing homelessness in a community setting if there are perceived safety concerns. For example, healthcare workers including palliative care workers, may decline to assess a patient in the community if it would involve entering a setting which is overcrowded, where drug-use equipment is present, or where violence is known to occur.[8]

In an in-patient setting, a person experiencing homelessness may be at risk of having their care discontinued if they engage in behaviour which breaks the institutional rules and conventions (e.g. smoking, drug use, alcohol use) or if they display anger or aggression (which they may display as a result of previous **traumatic** experiences).[26]

Challenges to healthcare-seeking among people experiencing homelessness

People experiencing homelessness are less likely to seek healthcare compared to the general population, and they do not engage with healthcare in the way we might usually expect from other patients. People experiencing homelessness may have lower levels of health literacy, educational attainment, lower cognitive capacity, limited access to material resources (e.g., phones; internet), transportation, and informal caregiving support. These barriers can make access to health and social care an arduous or insurmountable task.[26]

Also, someone experiencing homelessness may not prioritise their chronic health problems due to their sense of **survival imperative**. In other words, people experiencing homelessness – especially **multiple exclusion homelessness** – are taken up with the immediacy of their daily struggle for safe shelter and meals, meaning health needs are overlooked. Their ailments often progress untreated, and they may only present for medical attention at times of crisis, leading to increased numbers of emergency department visits and hospital admissions.[26,31]

Fear of discrimination and experiences of **trauma** also affect homeless people's capacity to seek healthcare. From Page 40, **trauma** is discussed in more detail.

Lack of options

Quality palliative care and end-of-life care should be focused on enhancing the patient's remaining life and working to meet the patient's needs and wishes prior to their death. For many people experiencing homelessness, their wishes at the end of their lives involve wanting to remain within their social network, including being in their homeless accommodation (e.g. shelters or B&Bs) if their health deteriorates. However, for many experiencing homelessness, the professional support they receive is from non-medical workers (e.g. shelter staff; outreach workers). Staff working in these environments do not typically have medical or care training when

a resident is unwell or has high care needs, and homeless accommodation is often not a practical setting to meet the person's care needs.[35]

There is also a lack of options for places for palliative and end-of-life care for people with life-limiting illness who are experiencing homelessness. They may be too young for care homes, and mainstream health services may struggle to cope with those who experience complex trauma and poor mental health and who use substances.[2]

People experiencing homelessness most often do not receive end-of-life care in **specialist palliative care** in-patient units or hospices, for reasons described above. People experiencing homelessness therefore often die alone in acute hospitals, or in other places such as alleys, streets, and vehicles. Clearly, this leads to poor quality of life and a poor quality of death. End-of-life wishes may not be fulfilled.[26]

Palliative care for people experiencing homelessness: the need for change

Homelessness is a form of **structural vulnerability** associated with a poor quality of life, poorer physical and mental health outcomes, complex needs, and reduced life expectancy. For these reasons, **homelessness is a life-limiting condition**. There are currently significant challenges for palliative care for people experiencing homelessness which result in poor or absent end-of-life care. These challenges should direct our focus as we develop solutions.

In their report **Dying in the Cold**, Marie Curie have presented recommendations for overcoming these challenges for people experiencing homelessness, with a Scottish focus:[2]

- The Scottish Government and Health and Social Care Partnerships should support improved access and provision of palliative and end-of-life care for people experiencing homelessness and terminal illness
- Training in palliative care should be provided for people working in homelessness services to aid identification of people with palliative care needs
- The Scottish Government should support the development and delivery of bereavement support for people experiencing homelessness

I agree with the above recommendations. I will go on to make my own recommendations for inclusive palliative care which I believe provide ways to tackle the challenges presented in this section, and which fit well with and build upon the recommendations made in the Marie Curie **Dying in the Cold** report.[2]

People in prison

People in prison in the UK

People in prison may be seen as on the very margins of society. The UK (excluding Northern Ireland) imprisons people at a higher rate than other Western European countries. The UK is the European country which most closely aligns with the United States of America "tough on crime" criminal justice policies.[36]

There are those who believe that the true purpose of prisons is for punishment, but this is not the (only) purpose. For example, the United Kingdom Ministry of Justice states the following:[37]

> **"We treat prisoners fairly, safely and decently whilst they are serving their sentences of imprisonment: offering them the chance to turn their lives around"[37]**

People in prison have the right to fair, safe, and decent treatment, including healthcare. **The United Nations Standard Minimum Rules for the Treatment of Prisoners (the "Mandela Rules")** Rule 24 states that healthcare available in prison should be equivalent to what is available in the community.[38] Failure to provide equivalent care for prisoners approaching the end of life is a violation of human rights principles.

> **"[..] Prisoners should enjoy the same standards of health care that are available in the community and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status."[38]**

The home nations of the UK have separate but similar prison services. The total UK prison population is approximately 97,800 people:[39]

- 87,900 in England and Wales
- 8,000 in Scotland
- 1,900 in Northern Ireland

Overall, the number of people in prison is increasing, despite falling crime rates.[40,41] England and Wales have the highest rate of prisoners in Western Europe. This includes pre-trial detainees, sentenced prisoners and those held in immigration removal centres.[42]

Demographic details of the UK prison population include:[3,42,43]

- the vast majority of people in prison (95%) are male
- more than a quarter of people in prison are from black or minority ethnic backgrounds (in contrast to black and minority ethnic groups making up only 14% the UK population)
- approximately 30% people in prison have some level of intellectual disability

- a very high proportion of people in prison have poor educational attainment (approximately half are below the level expected of an 11-year-old in reading)
- people in prison are more likely to have suffered social exclusion compared to the general population

Furthermore, older people are the fastest growing demographic within the prison population: the number of people in prison aged over 60 has more than tripled in the past 20 years.[3] There are also increasing numbers of the "oldest old" (aged 85 years and over). These increases are driven by the rise in sexual offence proceedings.[41,43]

Even for those released from prison, the experience 'inside' often results in loss of homes, possessions, employment and social connections. The homelessness **charity St Mungo's** estimated that 45% of their clients (people experiencing homelessness) have had contact with the criminal justice system.[44]

Healthcare in prisons

People in prison in the UK are patients of the National Health Service (NHS) and are entitled to access NHS services.[42] Consequently UK healthcare in prison is provided free of charge to the patient, but it must be approved by a prison doctor or other member of the health care team. Some prisons have in-patient units but most only have out-patient clinics. For more advanced investigations, treatment, or in-patient care, people in prison must be transferred to another prison with an in-patient unit or to hospital. However, transferring prisoners out of the prison is resource-intensive, usually requiring two prison officers to escort the patient throughout the visit.[41]

Illness and dying in prisons

The physical and mental health of people in prisons are poorer than the general population. For example, more than two thirds of the prison population have two or more diagnosed mental illnesses.[42]

Poor health is especially prevalent for older people in prison. Ninety per cent of the older prison population have at least one moderate or severe health condition. There are elderly people with dementia in prison who do not know where they are or why.[3] Older prisoners are at risk of violence and intimidation from other prisoners for reasons including medication theft[43] and the tough living conditions of prisons disproportionately affect older people.[45]

It is not simply the case that people already in poor health are more likely to be sent to prison: **the prison environment itself has an adverse effect on health**. Prisons are believed to cause premature ageing – with some prisoners believed to have the physical health of someone 10 years older than their chronological age.[42]

The adverse effects of prison on health are evident in the much lower average life expectancy for people in prison compared to the general population: the average age of death of people detained in prison in England is 56. The standardised mortality rate of prisoners is 50% higher than the general population.[46]

It is predicted that the prison population will continue to grow over the next few years, with a corresponding rise in the number of deaths in prison. The need for high-quality palliative care for people in prison is therefore likely to increase.[42]

Barriers to palliative and end of life care in prison

End-of-life care should be provided for everyone who needs it, regardless of social factors or care settings. In the UK, the Department of Health explicitly identified prisons as an area of need for end of life care.[42,47] Furthermore, the Prison and Probation Ombudsman recommends 'releasing terminally ill prisoners on compassionate grounds should be the norm unless security factors militate against it'.[42] Despite this, there is evidence that people in prisons are not uniformly receiving high quality palliative and end of life care when they need it.

The Prisons and Probation Ombudsman in the UK investigates all deaths in custody, to establish whether the treatment and care the deceased received prior to their death was of the expected quality standard. Hospice UK analysed this data for all people who died while in prison in England between October 2018 and December 2019. They uncovered worrying findings including:[3]

- care of people who died in prison was below the standards of what would be offered in the community
- restraints were used on people in prison at the end-of-life
- there were delayed or absent consideration of early compassionate release
- there was no mention of bereavement support in the data

Clearly, these findings are concerning. The principles of palliative care emphasise meeting the individual's choices and wishes towards the end of their life. Furthermore, support for the patient's loved ones, including bereavement support, is an important part of palliative care. However, the findings above demonstrate that a high standard of palliative and end-of-life care are not being achieved for people in prison. We must consider why this is the case.

There are significant barriers to providing good quality palliative and end-of-life care for people in prison. These include:[3,36,41-43,45,48]

- the rules of the prison limit autonomy including having wishes met even in relatively simple matters such as nutrition and activity
- the detrimental aspects of the prison environment can limit an individual's ability to cope and come to terms with their illness
- lack of available resources for providing care including medication, equipment, hospital beds, and continence pads
- the architecture and design of many prisons are unsuitable for people with mobility difficulties and limits space for specialist equipment
- compassionate release for people who wish to die at home is often denied and there may be lack of transparency around how the compassionate release decision is determined
- lack of training and availability for prison staff to administer medication
- lack of good working relationships between prisons and hospice services, meaning **specialist palliative care** and hospice staff not being granted access to prisons to provide care
- prison management and staff may not be aware of hospice services and the rights of people in prison to access hospice services

- the level of palliative and end of life care available varies depending on and may be influenced by geographical location, including whether there is a nearby hospice

Palliative care is also concerned with care of the loved ones of our patients. Prisoners' families and friends are likely to have specific needs in relation to their bereavement and may experience complex grieving processes. The stigma attached to being in prison may make it difficult for bereaved families to feel they can access local or national mainstream bereavement support services. Bereavement services might struggle to meet the specific needs of prisoners' families. It is also worth remembering that when death occurs in prison, particularly when the individual has served a long sentence, other prisoners may feel the loss keenly and need support to cope with their own bereavement.[42]

Palliative care for people in prison: the need for change

The end-of-life care needs of people in prison should be a major concern for palliative care. The need for high-quality palliative and end-of-life care is projected to increase, as a result of ongoing punitive sentencing practices, the ageing population, and the health inequities people have experienced prior to being in prison (due to overlapping **structural vulnerabilities**). It may be the case that improving attitudes and awareness of palliative and end-of-life care will lead to people in prison being discharged during their period of advancing illness, to be in the community ultimately at the time of their deaths. However, for now, people are ageing and/or getting sicker in prisons and dying in prisons – and so improving care access and provision in prisons remains a priority.

The Ambitions for Palliative & End of Life Care Partnership published the Dying Well in Custody Charter which sets out the following ambitions for end-of-life care of people in prison.[49]

Dying Well in Custody Charter - A national framework for action

Ambitions for end-of-life care in prison:

1. **Each person is seen as an individual**
2. **Each person gets fair access to care**
3. **Maximising comfort and wellbeing**
4. **Care is coordinated**
5. **All staff are prepared to care**
6. **Each community is prepared to care[49]**

These ambitions demonstrate awareness of the current challenges. I hope that, despite the challenges discussed in this section, the UK can move forward to soon see these ambitions met for people who are ageing, experiencing significant illness, and dying in prison. In this report, I go on to make recommendations for inclusive palliative care for people experiencing marginalisation, including those in prison, which I believe fit well with the above ambitions for end-of-life care in prison. The recommendations aim to inspire change which can overcome the current barriers to people in prison receiving the palliative and end-of-life care they need.

How we think about care

How should we think about care for people experiencing marginalisation?

Mainstream medicine is often measured in its ability to eliminate illnesses or to extend a person's life. This might include, for example, measuring success by counting the people with heart attacks treated with catheter treatment to relieve blockages in the heart's blood vessels. Or success might be measured by the number of patients living for long periods of time after chemotherapy treatments for certain types of cancer.

Palliative care is an approach which focuses on **quality of life** for people with life-limiting illness. For those of us working in palliative care, we can't measure what we do well in the same way as other areas of healthcare. We can't evaluate our successes by the number of people whose disease is cured because our work is helping people ***to live as well as possible*** with their illness, not in curing disease.

We should not base judgements of our successes on how long our patients live after we become involved in their care, because our care for patients is often focused on supporting the patient to receive excellent end-of-life care, possibly when life-extending treatments are no longer possible or wanted. Palliative care can therefore do an excellent job, with patients greatly benefiting from this care, without this good work being measurable in the same ways as mainstream healthcare.

How then should palliative care consider where its value lies? Firstly, we should value when we can take away a person's pain and other symptoms. The relief of physical and psychological suffering and the promotion of quality of life has immense value to patients and their loved ones. Our patients often feel comfortable knowing that, even if their condition is incurable, their physical and non-physical needs will be met before they die. We, as people working in palliative care, can also derive satisfaction from knowing we have treated a patient's symptoms.

However, we should be wary of valuing palliative care **only** on the ability to totally *eradicate* suffering. From such a view, in a situation where a person's suffering cannot be completely relieved, this might make us ask "what's the point of palliative care"?

This is especially pertinent when we think about people experiencing marginalisation, who may experience suffering which cannot feasibly be relieved before they die. For example, for a person nearing the end-of-life whose autonomy is restricted because of imprisonment, people working in palliative care often cannot directly eradicate this source of suffering.[1] Likewise, for a patient nearing the end-of-life who experiences suffering related to longstanding alcohol or drug dependency.

While we can work to reduce substance-associated harm, it is unlikely to be possible to eradicate the longstanding condition of their substance dependency in a short period prior to the end of their life. Furthermore, our patients may not wish us to try to change aspects of their lifestyle even if we believe they are preventing them from enjoying the best possible quality of life. For instance, people in prison may wish to receive end-of-life care in the prison to which they are

[1] Though we certainly should advocate for people in prison to receive compassionate release when appropriate

accustomed; people who are homeless may not wish to be removed from the street community they are integrated in; people who use drugs may not wish to stop using drugs.

In such cases, professionals may perceive a patient's circumstances as contributing to their suffering – but I believe palliative care continues to have immense value even when we cannot eliminate the sources of suffering. We can do valuable work by accompanying our patients in their suffering: not giving up on them, regardless of their circumstances.

Sisyphus was a character from Greek mythology who was sentenced to eternally push a boulder uphill. Whenever he reached the top of the hill, the boulder would roll off and Sisyphus had to push it back again. This left Sisyphus in an ever-lasting laborious situation where his endeavours were persistent yet futile.[50]

The lives of people experiencing marginalisation can contain many struggles. Our patients may have experienced multiple **traumas** in their lives. They may be in a state of feeling like Sisyphus, constantly pushing that boulder up the cliff, a never-ending ordeal. The "boulder" will be different for different people – perhaps including factors such as poverty, addiction, imprisonment, violence, racism, or a combination of all these – but the pattern of continuous hardship is similar across many people who experience marginalisation.

"Do all the good you can, by all the means you can, in all the ways you can, in all the places you can, at all the times you can, to all the people you can, as long as ever you can"[51]

This report presents recommendations for providing better palliative and end-of-life care for people experiencing marginalisation. Certainly, this must include finding better means to try to remove the problems which contribute to our patients' suffering.

For example, in Recommendation Three (Page 68) I make the case that people experiencing homelessness should be supported into stable housing as a priority, according to the principle of **Housing First**. In Recommendation Five (Page 77) I make the case that patients should be facilitated to have access to mental health care. These solutions-focused approaches involve ***doing things for*** our patient.

But we must also acknowledge we cannot remove all our patients' problems. We cannot take away every problem or eliminate every symptom. For patients experiencing marginalisation who are approaching the end of their life, elimination of sources of suffering might not be possible during their lifetime.

"I guess if you have to perpetually push that stone up the hill, it is better not to have to do it alone"[52]

For all patients, we should think about not only *doing* but how we can ***be with*** our patients who are perpetually pushing their "boulder" up the hill. In other words, though we cannot always eliminate the problems our patients face, we can keep them company on their journey and show understanding. I believe that through being with, we can bring comfort to our patients. This can have a positive impact, especially in the psychological and spiritual domains of suffering.

Being with is reflected in the recommendations made in this report. For example, in Recommendation One (Page 57) I emphasise the need to meet patients where they are, literally and figuratively, regardless of their ability to change their lifestyle. In Recommendation Seven (Page 85) I describe the need to create a space of peace for people to spend time in, to be accepted for who they are, to forget external pressures for a while, and to safely exist.

We cannot remove all our patients' problems – although we should try to do so as much as we can, if we can, and as far as the patient agrees this is what they want. Regardless of whether we can remove their sources of suffering or not, I believe we can ***reduce*** their suffering by accompanying them in their lives. At the very least, we can show people they are cared for and that we are not going to abandon them.

The value of palliative care is in the *care*. Care has its own value. I hope this report will encourage us to think more broadly about the value of care – and ultimately to find new and more inclusive ways to care.

Working at the deep end

Like everyone, people who are **structurally vulnerable** deserve the highest quality care palliative and end-of-life care. However, people experiencing marginalisation as a result of **structural vulnerabilities** like homelessness and imprisonment, do not always receive palliative care and may die in conditions far from ideal. I have described that people experiencing homelessness and people in prison have worse health and lower life expectancy than the general population and have complex palliative care needs when they approach the end of their lives.

Despite this high level of palliative care need, people from these **structurally vulnerable** groups experience significant barriers in accessing and receiving the high-quality palliative and end-of-life care they require.

For those of us trying to help people "**at the deep end**" it may feel we are trying to rescue them from being swept away by the currents of a powerful river. While this is vital work, we need other people working closer to the mouth of the river to find out why people are falling in and to stop this in the first place. I believe so many of the problems faced by people who are **structurally vulnerable** – including worse health outcomes and reduced life expectancy – could be solved by greater **equity** across all areas of society.

I am aware much work needs done to address the root causes of **structurally vulnerabilities**. I hope that, as a society, we can see high-level changes which lead to more compassionate and equitable approaches at the level of policy and public health, with positive outcomes in the domains of health, the justice system, housing, and quality of life.

I advocate for these higher-level changes to our structures to reduce people becoming **structurally vulnerable** in the first place. Certainly, I hope the work promoted by these recommendations can be seen as complementary to such root-cause work. Until we see societal changes which significantly promote **equity** for everyone, optimising care for people who are marginalised by our societal systems remains sadly necessary.

The remainder of this report will now focus on the important work of addressing development of more **equitable** palliative care for people experiencing marginalisation as a result of **structural vulnerabilities**, focusing on people who experience homelessness and people who are in prison.

In the next section, I discuss the role of **trauma** and explain why **trauma-informed** approaches are vital to achieving **equity** in palliative care. After establishing this foundation of **trauma-informed** care, I go on to explain the research process I undertook in this fellowship (starting from page 49), and then present the ten specific recommendations for inclusive **trauma-informed** approaches to palliative and end-of-life care (starting from Page 55).

A note on language in this report

Throughout this report, I intend to use humanising language. The language I have settled on results from conversations with my wonderful teachers throughout this research period, from my own reading, and from observations of **trauma-informed** care in practice. I realise there is no language which is universally accepted. Words that are seen as respectful and comfortable by one person may be seen as stigmatising or dehumanising by another. I apologise if there are times where my language causes offense. I ask you to remember it is my intention to champion the needs of the under-served and never to cause harm.

At times, the ideas mentioned in this report may be more relevant to one **structurally vulnerable** group in particular. To make this clear, I endeavour to use these terms when appropriate:

- People experiencing homelessness
- People in prison or incarcerated people
- People who use drugs or **PWUD**

I use the term people who use drugs (or **PWUD**) because I have found this to be an acceptable term by people who use drugs and/or those working in harm reduction. I find this term to be preferable to many other possible terms which may be inaccurate, too specific, medicalised, legalistic, alienating, or value-laden.

When I am referring to marginalised people generally, across **structurally vulnerable** groups, I endeavour to use the terms:

- People experiencing marginalisation
- People from marginalised communities

I generally use the word **patient** when describing the people who we care for. I acknowledge that the people supporting and caring for people experiencing marginalisation are often not healthcare professionals nor working specifically in a healthcare context. Furthermore, I am aware that healthcare environments and healthcare encounters (such as the doctor-patient relationship) can be seen as disempowering and may be reminiscent of past **trauma**. I in no way

wish to diminish these feelings or to take a paternalistic stance – in fact, my intention is the opposite.

By using the word **patient**, I wish to convey my understanding of this word: someone who we should be motivated to provide care for and whose wellbeing should be our priority. When I say **patients,** I mean we should be motivated to facilitate the best possible outcomes for the people we care for, without conditions about who the person is or what they have done in the past and without expecting anything in return. This should be a relationship where patient autonomy is centred.

I see this in stark contrast to a more traditional view where the patients are meant to be passive and acted upon by healthcare professionals. For me, the word **patient** makes the most sense in this context. I have chosen the term patient in preference to other terms such as *clients* or *service users* which, for me, can sound more like there is an expectation of a transactional relationship.

I hope this report will be read and used by all working in all fields working with people experiencing marginalisation, not just people working in health care or **specialist palliative care**. I have explained I believe that ***all*** people providing support and care for people experiencing life-threatening or life-limiting **structural vulnerabilities** are providing palliative care. However, I appreciate it may be unusual for you to think of the people you support as "patients", and so you may wish to substitute this word for another that works better for you.

Trauma

I believe it is impossible to meet the needs of marginalised people – including people experiencing homelessness and those in prison – without considering the role of **trauma**. It is important for those of us working in palliative care to understand **trauma**: firstly, **trauma-associated** symptoms are common generally for people accessing palliative care services.[53] The lasting effects of **trauma** predispose people to ill health and affect a person's ability to access the healthcare, including palliative care, that they need.

Furthermore, a history of **traumatic life experiences** is more likely to be present among people who are homeless[2] and people who are in prison.[54] That is why a major theme of this report is meeting the needs of people who have experienced **trauma**. Here I discuss the importance of considering trauma in our patients and why our solutions for improved care should be **trauma-informed**.

What is trauma?

> **"So much of what is called bad boundaries, trauma, and burnout in inner city work is in fact, responses to injustice, grief, and loss"** [34]

Trauma is a psychological and biological response which affects individuals due to distressing events outside the realm of normal human experience. **Traumatic experiences** can threaten a person's physical, emotional, or social well-being. Traumatic experiences are overwhelming,

cause feelings of fear, lack of control and helplessness, and are beyond a person's sense of their capacity to cope.[55]

Trauma can result from experiences such as abuse (including child abuse), neglect, experiencing or observing violence, accidents, natural disasters, war, sudden unexpected loss, and other life events outside of a person's control. A **traumatic experience** is not necessarily life-threatening – acts which threaten social and psychological integrity can also be traumatising.

People from different cultural backgrounds may experience trauma differently, and what is considered traumatic in one culture may not be so for someone from another cultural background.[56]

There are a number of dimensions of trauma, including magnitude, complexity, frequency, and duration. Trauma does not only affect individuals in the present: it can affect descendants of traumatised individuals or populations through social, psychological, and perhaps genetic repercussions for future generations.[57]

It is estimated up to 90% of older adults have experienced a traumatic event in their lifetime. In particular, **Adverse Childhood Experiences (ACEs)** are extremely common, i.e. traumatic experiences occurring in the life of a person before the age of 18 years old. Approximately half of people in England and Wales have experienced one **ACE**, and approximately 10% have experienced have four or more **ACEs**.[58]

Trauma is also disproportionately experienced by those already facing societal inequalities including socioeconomically disadvantaged groups, women, racialised minorities, sexual and gender minority groups, people who live in unsafe neighbourhoods, and people with lower levels of educational attainment. Discrimination and bigotry (e.g. racism) and financial stress are themselves traumatic stressors.[57]

Eighty-five percent of UK born people with multiple-exclusion homelessness have experienced childhood trauma.[29]

A relatively small proportion of people who have experienced trauma will go on to have a formal psychiatric diagnosis of **Post-Traumatic Stress Disorder (PTSD)**. To obtain a diagnosis of **PTSD**, the affected person needs to have a combination of intrusive symptoms (e.g. involuntary memories or "flashbacks") AND persistent avoidance of stimuli associated with the traumatic event AND negative alterations in thinking or mood (e.g. memory losses) AND marked alteration in arousal or activity (e.g. hypervigilance) for more than one month which causes significant impairment in functioning.[59]

More commonly, people who have experienced trauma are affected by one or more of these **trauma-associated** symptoms but without meeting the full diagnostic criteria for **PTSD**. When providing care for our patients, we may observe people who have been traumatised can display sudden explosive anger, or perhaps self-discharge from care or avoid care services altogether. By understanding that **trauma-associated** symptoms are present, we can see why our patients may behave the way they do.

Traumatised people become hypervigilant to threats and engage in high-risk behaviour. When reminded of past traumatic experiences, they can find it difficult to tell the difference between the past and present – they feel that the traumatic event is happening again. Lasting neuro-biological changes in traumatised individuals can be profound and may include:[5,60]

- changes to brain architecture including hyper-activation to emotional stimuli and reduced volume in areas controlling emotional regulation
- reduced grey-matter volume
- long-term increases in cardiovascular reactivity to traumatic stimuli
- increased autonomic nervous system ("fight or flight") response
- greater catecholamine levels (dopamine, epinephrine, and norepinephrine) associated with a state of hyperarousal

These changes result in a person becoming biologically primed to respond to minor stresses, with a low level of tolerance. The affected person is sensitised to react to perceived threats, especially those reminiscent of past traumatic events. Traumatised individuals also often lack the ability to self-soothe their distress. The consequences can be an easily triggered sense of terror and panic. Periods of heightened emotions can then lead to the affected person using coping strategies such as substance use and self-harm. This pattern of behaviour often causes low self-esteem, shame, and guilt.[5,60]

We might think that the reactions and behaviours of traumatised people can be irrational. However, we must remember that the behaviour of traumatised people does not represent bad character or lack of willpower – it is caused by biological changes.[60] Trauma is not just in someone's mind but is a lasting neuro-biological state. People affected by trauma cannot "just get over it" and we must be responsive to their needs and sensitive to their condition.

Trauma and its effects on health and quality of life

Understanding trauma should be the business of all healthcare workers and all working with marginalised groups. Trauma is a major public health concern because it has a significant negative impact on physical and mental health outcomes, access to healthcare, socioeconomic status, and numerous social issues.

The consequences of trauma include:[4]

- higher risk of further harm
- higher rates of substance use
- higher risk of mental health difficulties
- higher rates of preventable disease
- higher risk of early death
- educational difficulties
- contact with the criminal justice system
- reduced opportunities

There is a significant overlap between **ACEs (Adverse Childhood Experiences)** or other traumatic life events, and homelessness, contact with the criminal justice system, and **multiple exclusion**.[29]

Much of our contemporary awareness of trauma and its detrimental outcomes comes from the **Adverse Childhood Experiences (ACE)** study conducted in the USA in the 1990s. The **ACE** Study was one of the largest investigations conducted to assess associations between negative childhood experiences and adult health. The researchers studied the background of many thousands of people and determined **ACEs** were vastly more common than recognised. They found **ACES** coexisting and directly linked to:

- substance use
- mental health problems
- a range of chronic diseases such as diabetes and cancer

The study identified a strong correlation between **ACEs** and these negative outcomes, which often occurred many decades later.[61]

Why care may be traumatising and retraumatising

Experiences of healthcare can themselves be **traumatic**. For those with life-limiting illnesses who engage with the healthcare system, there are a number of ways that treatment and healthcare can be traumatising. During the journey of someone diagnosed with life-limiting illness, they will go through a series of consultations, examinations, exposure of the body, intrusive procedures, and challenging or confronting communication.[62]

For people who have already experienced significant trauma, we must be aware these healthcare experiences can trigger or exacerbate feelings associated with previous trauma. Our care approaches may cause people to experience **retraumatisation**.[5]

Retraumatisation means to become traumatised again. Retraumatisation occurs when something in a present experience is reminiscent of a past traumatic experience. This may occur when the affected person is unable to stop or escape a perceived or actual personal threat.[5]

Traumatic experiences make it difficult to trust. Examinations, personal care, investigations, procedures, and administration of medication may be reminiscent of previous traumatic experiences. **Retraumatisation** may be worsened in environments where there is seclusion, use of restraints, forced medication administration and constant observation.[5]

We should also consider that the care environment and relationships between patients and healthcare providers can be **retraumatising** in less obvious ways. There can be a power imbalance between patient and healthcare workers, making a traumatised person feel a sense of powerlessness and vulnerability. This can be exacerbated if the patient's views and preferences are disregarded, or boundaries not respected. This can explain why some who have experienced trauma avoid formal services or engage inconsistently, making it more challenging to develop and maintain therapeutic relationships.

For those working in palliative care, we must also be aware that a diagnosis of a life-threatening illness may mimic previous trauma a person has experienced. **Retraumatisation** can occur because the patient is caused to examine their life events and be confronted by traumatic

memories. Moreover, evidence suggests that memories of old traumas and **trauma-associated** symptoms may be reactivated as part of normal aging, and these may be exacerbated by illness and life stress.[53]

Trauma-informed approaches

Trauma-informed approaches involve moving from thinking 'What is wrong with you?' to considering 'What happened to you?'[63]

Clearly **trauma** is a pervasive problem with detrimental effects on health and quality of life, and significant impact on access to healthcare, including palliative care, for people affected by trauma. In becoming more inclusive of people experiencing marginalisation, we must consider how we adapt to meet the needs of people who have been traumatised and to avoid approaches which traumatise or **retraumatise**.

When we as carers and organisations understand and acknowledge the effects of trauma on people and incorporate this into their practice, our approaches are **trauma-informed**. The Substance Abuse and Mental Health Services Administration (SAMHSA) of the USA Department of Health and Human Services defines being **trauma-informed** as follows:[6]

"A program, organisation, or system that is trauma-informed realises the widespread impact of trauma and understands potential paths for recovery; recognises the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization" [6]

Rather than being a specific service or set of rules, **trauma-informed approaches** are a process of organisational change aiming to create environments and relationships which promote care and prevent **retraumatisation**.[5] SAMHSA emphasises adoption of six key principles for **trauma-informed** approaches, as opposed to rigidly following a prescribed protocol. The six fundamental **trauma-informed** principles they set out are:[6]

1. **Safety** – physical and psychological safety within an organisation for staff and the people they serve

2. **Trustworthiness and Transparency** – decisions are transparent in order to build and maintain trust with the people served by an organisation

3. **Peer Support** – individuals with lived experience of trauma have a key role in building trust, enhancing collaboration, and promoting healing

4. **Collaboration and Mutuality** – reducing power disparities between staff and the people served by an organisation

5. **Empowerment, Voice, and Choice** – individual strengths and experiences are recognised and valued throughout the organisation

6. **Cultural, Historical, and Gender Issues** – actively countering stereotypes and biases, and recognising and addressing historical trauma

We should remember that people who have been traumatised experience at least one **trauma-associated** symptom but most do not have a formal diagnosis of **Post-Traumatic Stress Disorder (PTSD)** nor meet the full diagnostic criteria.

People do not need to have to have a diagnosis of PTSD to benefit from trauma-informed approaches. In taking a **trauma-informed** approach, we do not need to know the details of other people's trauma. We presume that everyone has experienced trauma in their life.

Trauma-informed care approaches DO NOT require disclosure of trauma

We must be prepared to be accommodate people's needs, but we do not need to know the underlying reasons.

Implementing **trauma-informed** approaches will require robust staff education, organisational support, and resource investment. Although the emphasis of **trauma-informed** approaches is on how care is provided, a necessary component is that those delivering the care also feel safe and do not experience traumatisation or **re-traumatisation** in their work. **Vicarious trauma** usually refers to the effect of working with traumatised people on practitioners. But organisations which are not **trauma-informed** can themselves cause **vicarious trauma** in staff.[5]

The value of **trauma-informed approaches** has been widely recognised. For example, in Scotland there is a stated ambition of being "a **trauma-informed** and responsive nation and workforce, that is capable of recognising where people are affected by trauma and adversity, that is able to respond in ways that prevent further harm and support recovery, and can address inequalities and improve life chances".[64]

Nevertheless, the explicit application of **trauma-informed approaches** in UK palliative care is generally inconsistent or absent. This has been highlighted as a vital area for improvement for people experiencing marginalisation, including for people experiencing homelessness.[2]

This report argues for inclusive palliative and end-of-life care for people experiencing marginalisation, by putting forward recommendations. These recommendations aim to integrate **trauma-informed** principles.

What this report is not

This report will **not** cover work to heal underlying trauma. Although I advocate for being **trauma-informed**, it is important to recognise that **trauma-informed approaches** do not equate to treatment.

Trauma-informed approaches are not the same as trauma treatment. In providing trauma-informed care, we are not presuming to be competent in psychological treatment of trauma

I hope this report will encourage those of us in palliative care to adopt **trauma-informed approaches**, which we can all do as non-trauma specialists. Through an inclusive and **trauma-informed** environment I hope we will have a holistic, therapeutic effect on our patients. However, as non-trauma specialists we should not be attempting to ***treat*** trauma.

Mental health care for people who have experienced trauma is a specialist field and we should be prepared to signpost to mental health professionals. Better yet, integration of mental health services into palliative care would allow for more streamlined access to mental health professionals for people accessing palliative care including, when appropriate, better access to trauma treatment from trained professionals (a recommendation I make in this report; Recommendation Five). I must be clear that the rest of us – who are not trained in this area – should not be attempting to treat trauma itself. More information on different levels of expertise that exist in this area is found on Page 78.

HIV and AIDS

When discussing **trauma** and marginalisation, I must acknowledge the treatment of people affected by HIV and AIDS: the stigma, neglect, and abuse that people with HIV/AIDS have historically experienced. HIV and AIDS remains an important public health concern worldwide. People living in the Global North can be thankful HIV is now most often not considered a life-limiting condition in high-income countries. Despite this, I believe HIV/AIDS remains an important issue for us working in the palliative care when considering the values we wish to cultivate.

Firstly, HIV remains a life limiting illness in some parts of the world especially in times of instability. This includes people living in settings affected by conflict or who are refugees, where access to antiretroviral medication is limited.[65] Secondly, there is overlap between marginalised group, and we must provide care for people experiencing multiple disadvantages. Those at risk of marginalisation due to, for example, homelessness, may also be at risk of marginalisation due to HIV.[30,31]

Thirdly, many of the initiatives and activism for other marginalised patients today have their roots in the work that started during the AIDS crisis of the late 20th century. This has been reflected in the experiences I had during this fellowship. I have been privileged to meet some amazingly compassionate and motivated people who provided care for people dying of AIDS in the 1980s and 1990s, and are still caring for marginalised patients today, including the homeless or those in prison.

"I went back to my college reunion … there were so many people missing. So many young men had died because of AIDS" - Anonymous, shared with me by someone I met during my fellowship

Furthermore, many current initiatives were conceived as measures to provide much needed care for people dying of AIDS, unavailable elsewhere.

These include:

- California Medical Facility Prison Hospice, Vacaville, California (Box Three, Page 60)
- Diane Morrison Hospice, Ottawa, Canada (Box Twelve, Page 75)
- Casey House in Toronto, Canada (Box Eighteen, Page 88)

We cannot underestimate the **trauma** caused to a generation of people affected by HIV and AIDS, and the **trauma** of those who saw their friends, relatives, partners and patients die without being given the care they deserve. We also must acknowledge the **trauma** that people with HIV still experience from stigma and ostracism.

I believe there is a great deal that we can learn in the present day from those who forged their way through caring for people with AIDS when no one else would. I thank them for their teaching and leadership.

The need for change

This report advocates for **equitable** palliative care for people experiencing marginalisation, focusing mainly on two specific groups: people experiencing homelessness and people in prison. I believe through **trauma-informed approaches** we can practice a way which avoids traumatisation and **retraumatisation**. This will make care more **equitable** – accommodating the unique needs of people experiencing marginalisation and adapting our care so it can be accessible and beneficial to those under-served.

In the next section I begin to present the research approach I took to discover inclusive palliative care approaches. I present the research aims of my Fellowship (Page 49), the discovery method I undertook (Page 50), and more information about who I am and my values (Page 53).

After this, I present the findings of this project: my recommendations for inclusive palliative care, integrating the principles of **trauma-informed approaches** starting on Page 55.

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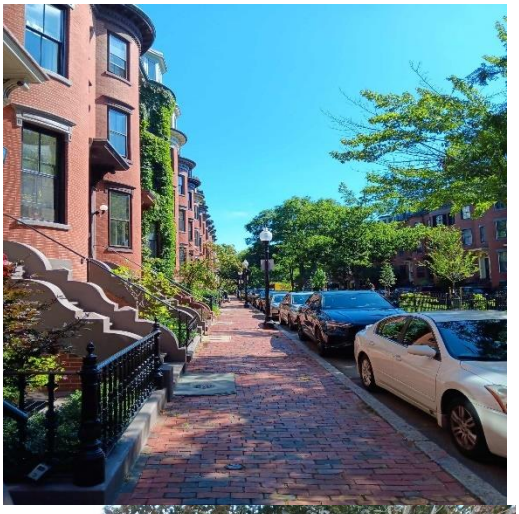
Aims

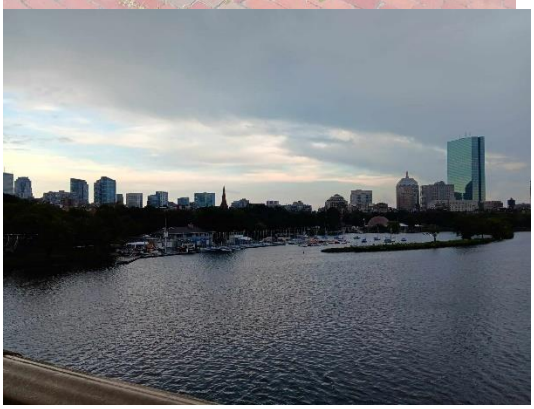
This report presents the findings from my Churchill Fellowship research. My fellowship aimed to develop recommendations for inclusive approaches to palliative care for people experiencing marginalisation in the UK, through learning from care delivery elsewhere in the world. My learning journey addressed these exploratory research aims:

- To observe practice in international centres which provide palliative care for **structurally vulnerable** patients, including through **trauma-informed approaches**
- To learn how to optimally provide holistic, **trauma-Informed** palliative care for **structurally vulnerable** groups who have traditionally been neglected, principally including:
    - people experiencing homelessness
    - people who are in prison
- To learn about the day-to-day running and scope of these services, including:
    - how patient contact and care is initiated and maintained
    - how the centres' multi-disciplinary teams collaborate effectively
    - how **trauma-informed** principles are integrated into practice
- To learn about the model, development, governance and funding of such services, to better understand what organisational factors are needed for their successful running within wider health services
- To examine how lessons learned from the above activities may be integrated into the UK palliative care and wider health care contexts to inform and improve UK systems, in order to generate recommendations for improved practice in the UK

The ultimate goal of this work is for palliative care to be optimised to meet the needs of patients who are neglected by current models, including people experiencing homelessness and people in prison. My hope is for such change to result in less suffering for everyone – our patients, those caring for our patients, and our entire society.

Methods





To meet my aims I conducted a six-week exploratory travelling fellowship to learn from centres, organisations or teams in the USA and Canada.

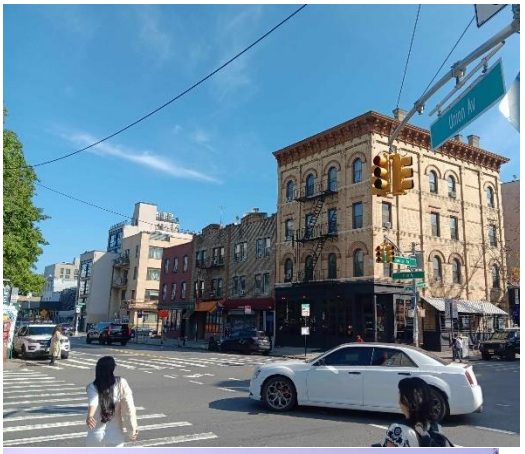
This principally comprised exploratory visits to:

- Commonwealth Care Alliance, Massachusetts, USA
- Center for Urban Community Services and Janian Medical Care, New York City, New York, USA
- Humane Prison Hospice Project, California, USA
- Equity in Palliative Approaches to Care and Palliative Outreach Resource Team, Victoria, British Columbia, Canada
- Ottawa Inner City Health Inc including Diane Morrison Hospice, Ottawa, Ontario, Canada
- Palliative Education and Care for the Homeless (PEACH), Toronto, Ontario, Canada

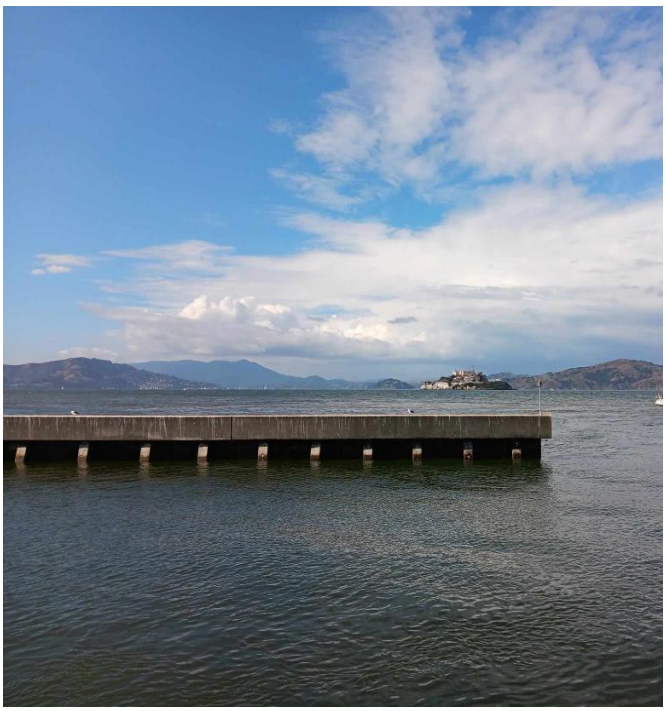
During these visits, I was privileged to observe practice, meet with patients or clients, and meet with professionals and organisers to gain an understanding of the structure and history of these initiatives and learn about their philosophies of care.

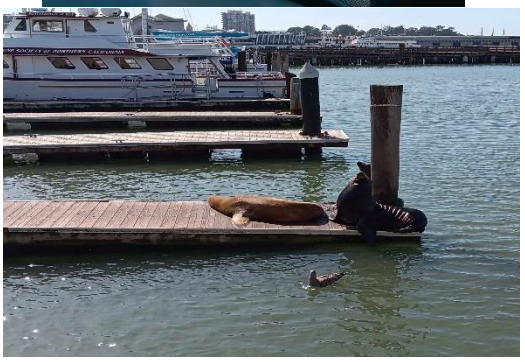
Throughout this journey, I have been aware that services that work in other contexts may not be directly transferable to the UK. I therefore have focused on distilling this learning into salient lessons to take forward in the UK rather than going into great detail about organisations in other countries.

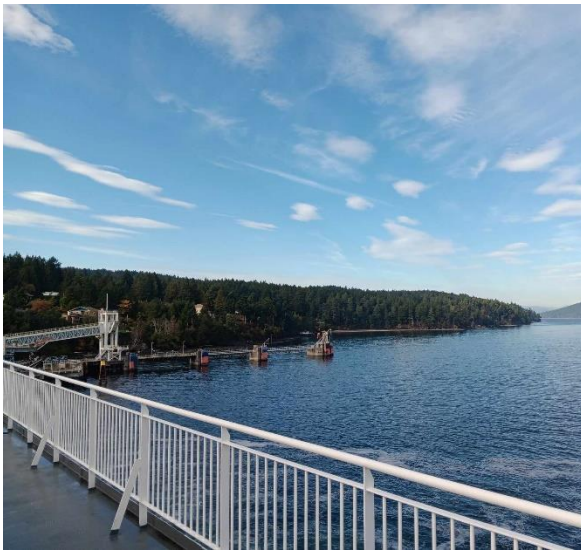
Left: Boston, MA, USA, including Harriet Tubman memorial statue

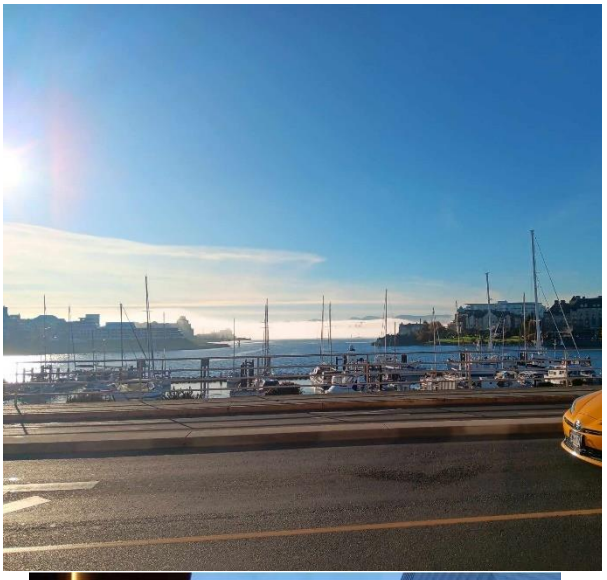


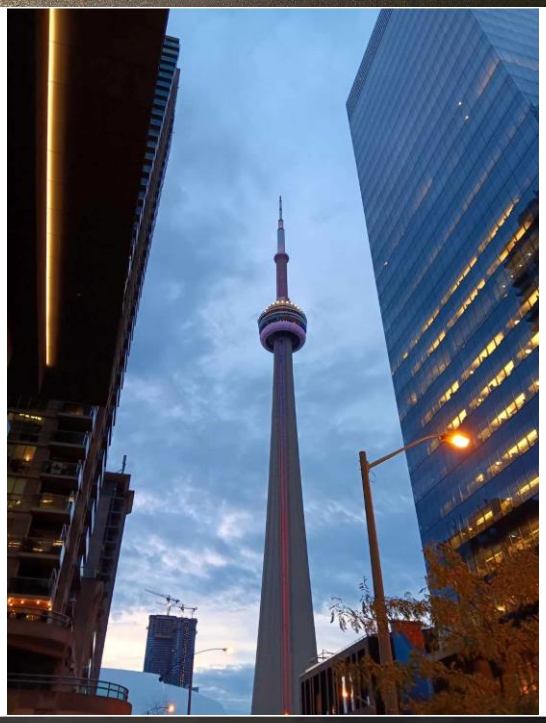
Above: New York City, NY, USA. Below: California, USA. Copyright Shaun Peter Qureshi







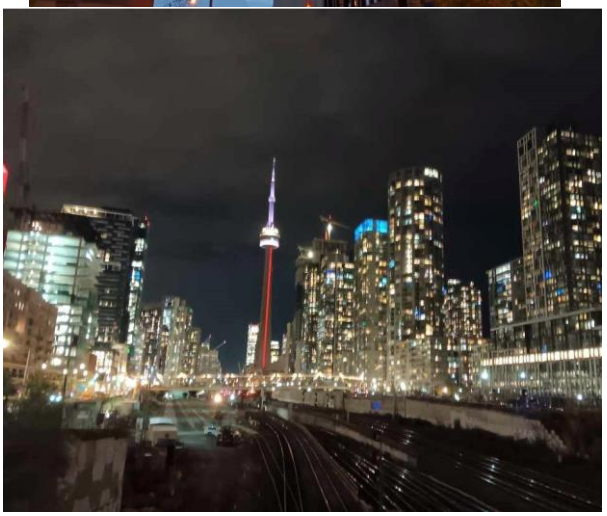




Above: British Columbia, Canada

Right and bottom right: Toronto, Canada.
Below: Company T-shirt of Ottawa Inner City Health, Canada.

Images copyright Shaun Peter Qureshi



About me

The focus of this work is not on me but on **structurally vulnerable** people experiencing marginalisation. When reading and interpreting my work, it may be helpful to have some insight into the person who conducted this research and developed the recommendations – so I present some information about myself and my motivation and values.

I come from Scotland, a country where one in four children, one in five working aged people, and 15% of pensioners live in poverty. There are huge inequalities in wealth distribution, with the richest 1% owning more property than the least wealthy 50% of people combined. We have the lowest life expectancy in Western Europe and the highest rate of drug death in the whole of Europe.[66,67]

I devised this project to work on issues I care deeply about. Growing up in Scotland, social deprivation was all around. As an adolescent, I observed my peers engaging in unhealthy behaviours such as substance use and violence, leading to disease, incarceration, and addiction – exacerbating cycles of poverty. I went on to study medicine as I believed this would facilitate a career where I could help the disadvantaged.

The image on the left reflects my professional background. As a physician I have worked as a doctor all over Scotland – from very rural to inner-city work – with some experience working in socially disadvantaged areas of the North of England too. In the course of my training, I realised our medical and healthcare models are based on the misconception that we can always help others by treating disease in straightforward ways. In reality, many people have chronic illnesses which cannot be simply treated. The most socio-economically disadvantaged people are also those with the worst health, and their conditions are made more complex by social issues, often inseparable from their experience of illness.

It was frustrating that, for many patients, I felt like I was merely "papering over the cracks" when they were at points of crisis, rather than providing longer term solutions that could improve the patients' quality of life. I was frustrated, also, that the set-up of our healthcare system was so focused on "firefighting" crises that it often did not allow for recognition of when a patient's chronic condition was progressively worsening – and when a patient was dying.

These experiences made me want to study the challenges internally. I completed a doctoral thesis at the University of Edinburgh, researching how the organisation and competing demands of general hospitals influence how physicians recognise or fail to recognise when a patient is dying. Through this experience, I developed as a researcher and deepened my understanding of how our inflexible systems may actually impede the provision of care that patients need. This

gave me a greater capacity to question the problems affecting our society, and an analytical lens with which to think about *how* some people are disadvantaged.

I chose palliative care as my medical specialty because this field acknowledges the importance of the whole person. The explicit emphasis of enhancing quality of life appeals to my understanding of what it means to be a doctor. I believe awareness of social justice should be central to a doctor's practice and identity. In my practice as a palliative care physician, I have served severely disadvantaged communities in Scotland, including communities with life expectancies among the lowest in Europe. I have seen extreme levels of social deprivation combined with severe illness. Furthermore, I saw the disparity between the need for care among those experiencing the highest levels of disadvantage – including people experiencing homelessness and those who use drugs – and the low quantity and quality of care they actually receive. I was frustrated by feeling there were so many in need who I was unable to reach (due to the barriers I have discussed in this report).

It was disillusioning to realise we are far from reaching the aspiration that everyone who needs palliative care can access it. My desire to do something constructive about this led me to undertake this work.

My thought processes, interpretations, and opinions in this report will naturally have been influenced by my life experiences – professional and personal – including ways I may not be conscious of. I *am* conscious in my work of the importance of promoting justice for the people who have traditionally been discriminated against, exploited, disenfranchised, or oppressed. Promoting class justice, disability justice, and justice for racialised minorities are important to me. I have witnessed and experienced that injustice and bigotry in these domains can be present in the healthcare sector, and, unfortunately, in palliative care organisations and among individuals working in palliative care.

It is my sincere hope that this report can contribute to positive change which will benefit those who are currently under-served, improving palliative care provision to people experiencing marginalisation. I hope that this change will involve healthcare including palliative care settings becoming healthier, **trauma-informed**, and positive places which are equitable and effective for all patients and inclusive and safe for all people who work there.

Recommendations

Through my Fellowship, which involved exploratory visits to the North American organisations listed on Page 50, I have gained invaluable learning and experience. Following reflection on how this learning can be employed in the context of the UK, I have devised the following recommendations. Here, I present these ten recommendations which I believe promotes inclusive approaches to palliative care for those experiencing marginalisation in the UK.

Applying my recommendations

It is my hope these recommendations will be of use to everyone providing palliative care for people experiencing marginalisation. My concept of palliative care is of enhancing the quality of life for people who have a life-threatening condition, which includes homelessness or being in prison, as these are life-threatening or life-limiting conditions much of the time.

Palliative care for people experiencing marginalisation is therefore not just the work of people in healthcare or palliative care organisations – palliative care is also being delivered by people working in the homeless and prison sectors who do vital work to enhance the quality of life for people with significant and life-threatening conditions (see Page 17).

In other words, these palliative care recommendations are intended for: every person working in **specialist palliative care**, every person working in healthcare, **and** every person working to care for and support people experiencing marginalisation across any all and sectors.

In forming these recommendations, I aim to provide ways to put into practice the essential principles of **trauma-informed approaches**: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; sensitivity to cultural, historical, and gender Issues.

As I explained earlier, these recommendations are in no way meant to suggest that people working in palliative care without specific mental health training in the field of psychological trauma are able to treat or cure trauma. Likewise, applying **trauma-informed** recommendations does not require patients to divulge previous traumatic experiences, or for caregivers to necessarily know details of sources of trauma. Taking inclusive approaches to palliative care involves showing awareness that everyone has likely experienced trauma in their life. I feel it important to treat everyone (patients and staff) compassionately, to be adaptive and avoid traumatisation and **retraumatisation**.

These are recommendations, not protocols. The recommendations are deliberately conveyed at the level of general principles. They are not meant to be prescriptive or limiting. On the contrary, I hope people using this report will find new, creative and expansive ways to take these recommendations on board and integrate them into their practice.

Every person and organisation working in palliative care and with those experiencing marginalisation should consider the different ways these recommendations might be adopted. It may depend on many individual factors such as the people being cared for, the resources available, and local structures and funding. I am aware some recommendations may be more straightforward to follow, while others might need further investment of resources or applications for funding. Or even changes in legal rules or jurisdictions (e.g. harm reduction approaches described in Recommendation Four).

There may be individuals or organisations already be following many of these recommendations. For others, the practices recommended may be counter-cultural or even shocking (if so, please remember Recommendation Ten, about the need for **unlearning** and cultural change).

I hope you will consider these recommendations carefully and have an open mind about how some or all of these ideas can be put into practice in your context. I am interested to hear about what changes might be possible for you and your work and I am excited to learn about any changes which have a positive impact on the people you care for.

Remember any palliative care is a revolutionary practice – let's be revolutionary and make changes so everyone gets the care they deserve!

List of recommendations

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Recommendation Two Peer-to-peer care and support (Page 62)

Recommendation Three. Prioritise housing as healthcare (Page 68)

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Recommendation One: Early contact and persistency – to meet people where they are

To reach marginalised individuals needing palliative care, adopt inclusive strategies that are proactive, easily accessible, establish early contact, remain persistent – and always meet people where they are

Accessing care: the current situation

Healthcare is organised according to convention. To receive care, a person generally abides by established norms set by healthcare institutions. Healthcare consultations are normally by appointment, normally physically situated inside a healthcare setting, and scheduled at an exact time and date. In the UK if the patient does not come to the appointment at the given time, they are labelled as "DNA" (Did Not Attend), may receive a letter telling them off for wasting healthcare resources, and may not be offered a further appointment. The responsibility to make it to the appointment and receive healthcare rests on the patient, who must conform to the rules set by healthcare professionals.

In the UK, access to **specialist palliative care** is only given according to established rules, in certain circumstances. For example, specialist palliative care services will not automatically assess or provide care for patients, even if they are being cared for by another clinical team due to a life-threatening illness.

Instead, specialist palliative care teams must receive a *referral* from another professional, e.g. a doctor caring for a patient as a hospital in-patient or at home. In the UK, for a patient to receive **specialist palliative care** before death, several interactions with healthcare professionals and processes must successfully take place. Palliative care services may have different criteria for whether they "accept" a referral into their service.

I have observed referrals for patients be declined by **specialist palliative care** services – reasons have included the patient is "not complex enough", the patient has "no clear diagnosis", or the patient is "not clearly dying yet".

To achieve positive patient results, we know palliative care must be an early intervention. Palliative care is effective when there is time to make a positive difference to the quality of the patient's remaining life. Therefore, for the best outcome, palliative care approaches should start well in advance of the patient's death. Unfortunately, this is often not the case. Approx 25% of people in the UK die without access to the palliative and end-of-life care they need.[22] This is particularly relevant for anyone marginalised.

Access to care for people experiencing marginalisation

For patients experiencing marginalisation there are barriers to accessing care. People who are affected by past **trauma** may not behave in the way we expect patients to. To engage with conventional healthcare, many factors must already be in place, including:

- fluency in the English language
- registration with a general practitioner / primary care provider

- access to a means of transport to get to healthcare appointments or money to pay for transport
- a fixed address to securely receive letters
- a telephone with which to make and receive telephone calls and receive text messages
- sufficient literacy to read and understand written information
- sufficient health literacy to identify one's own health needs and abnormal symptoms
- having the means to plan in advance and organise time
- ability to self-advocate for medical attention
- capacity to prioritise health needs in relation to other needs, e.g. finding sufficient food, a place to sleep, a supply of substances
- capacity to trust strangers, especially those who may be perceived as authority figures (including healthcare professionals) and feel comfortable in healthcare settings
- capacity to behave in the expected way in formal settings, e.g. not speaking loudly, having a tidy comportment, and not showing signs of being under the influence of alcohol or drugs

Given the above, we can understand conventional forms of care provision may not be accessible or sufficiently inclusive for patients experiencing marginalisation. We should overcome these barriers by taking inclusive approaches.

Proactive engagement

Instead of waiting for patients to seek medical attention, and for eventual patient referrals to palliative care, a more inclusive approach should involve pro-actively engaging with patients. I have observed such approaches during my fellowship demonstrated by the **Center for Urban Community Services (CUCS)** Street Medicine team in Brooklyn, New York City, USA. One way that the CUCS Street Medicine team engages with patients is by meeting with and introducing themselves to people experiencing street homelessness in Brooklyn. This leads to the patient being engaged with the service and being given access to healthcare, without necessitating an external referral or the patient needing to initiate contact.

Another model of proactive engagement is demonstrated by the palliative care programme of **Commonwealth Care Alliance (CCA)** in Massachusetts, USA (see Box Two, Page 59). CCA accesses medical records of patients experiencing socioeconomic disadvantage and applies a proprietary computer algorithm to identify patients who are likely to have palliative care needs and who would benefit from the palliative care programme.

This allows CCA to contact clinician colleagues already involved in the patients' care to discuss and facilitate the referral to the palliative care programme as appropriate. The adoption of similar approaches in the UK would allow for pro-active, early engagement in palliative care with patients experiencing marginalisation without waiting for another professional to realise palliative care is needed.

Box One. US Government funded health insurance

Medicare

Federal health insurance for anyone age ≥65 and some people with certain disabilities or conditions

Medicaid

Federal and state health insurance for some people with limited income and financial resources.

Patients who "Dual-eligible" for Medicare and Medicaid are disproportionately from minority ethnic backgrounds, and often face challenges accessing health services including palliative care

Box Two. Commonwealth Care Alliance, Massachusetts, USA

Commonwealth Care Alliance (CCA), a community-based, integrated healthcare organisation, provides medical, behavioural health, and social support services for people dually eligible for **Medicare** and **Medicaid** (see Box One above) as well as other products for Medicare recipients. This remit allows for provision to disadvantaged patients who otherwise would not receive healthcare. CCA has a palliative care team, which directly provides palliative care input to its patients, including community reviews of patients wherever needed, be it at the patient's home or in a shelter.

CCA uses a proprietary artificial intelligence programme to interpret healthcare records of all registered patients, to identify patients who are at risk of deterioration in their condition and/or who likely have palliative care needs. This model is advantageous as it prompts collaboration with the clinicians and helps initiate the referral, and allows for palliative care to be offered to patients who need it but do not have stable lifestyles and/or may not normally engage with healthcare in a way which may be expected in mainstream healthcare.

I observed that the CCA model allowed palliative care to be offered to patients regardless of diagnosis, with many patients with non-cancer diagnoses receiving palliative care – proportionally greater than I have come to expect from **specialist palliative care** services in the UK. Palliative care intervention is also offered early in the patient's **trajectory**. This allows for a trusting relationship to be built up over time, for there to be an opportunity to make a positive difference to the patient's quality of remaining life, and to have sufficient time for discussions about goals of care and wishes at the end-of-life in advance of dying.

Low barriers to referral and acceptance

Inclusive approaches should also include palliative services having low barriers to referral and acceptance of referrals. This includes being open to accept referral from all sources. For example, a person experiencing homelessness may have developed a health condition and be getting sicker but may not have sought or received medical help. However other people who know her/him – like social workers, case workers, shelter staff, or friends – may have noticed she/he has a deteriorating condition and be worried. We should be open to considering referrals from all

sources. Furthermore, everyone who works with people experiencing marginalisation should be educated about palliative care and identifying when the people they support may have palliative care needs (also see Recommendation Eight, Page 88).

Reducing barriers also involves having an open mind about acceptance of referrals. People experiencing marginalisation might not have a defined diagnosis and it may not be clear how close they are to the end of their life. We must be aware the **social determinants of health** and illness: homelessness is itself a life-limiting condition. Imprisonment worsens health and accelerates ageing. Likewise, drug use is a condition which has the potential to reduce people's life expectancy. We should recognise when people experiencing marginalisation have palliative care needs and not be restricted by the standards of exact referral criteria or seeking a specific diagnosis.

Meeting patients where they are

People working in palliative care should be open to meet patients where they are, wherever they are. This should include openness to go out and meet, assess, and care for patients in any location, wherever is needed. If we wish to be inclusive of patients experiencing marginalisation, we should be inclusive of meeting people in prisons, in shelters, or on the street.

This open attitude to meeting patients where they are goes beyond physical location: we should meet patients where they are in their stage of disease and whatever other factors in their life they come with. We should accept a patient for who they are and where they are in their lives.

In Toronto, Canada, I had the opportunity to learn from the organisation **Palliative Education and Care for the Homeless (PEACH)** (See Box Three below) which exemplifies the application of these principles.[68] In particular, I observed how having a low barrier to access and dedication to meeting and accepting patients where they have resulted in benefits, including early initiation of patient contact, building trusting relationships with patients, and effective palliative care delivery.

Box Three. Palliative Education And Care for the Homeless (PEACH), Toronto, Ontario, Canada

PEACH is a community palliative care team providing care for people experiencing **structural vulnerabilities** in Toronto. It operates due to a partnership between the Inner City Health Associates (an organisation that advances health **equity** for people experiencing homelessness), Kensington Health (an organisation that provides community-based psychosocial & hospice care) & Home & Community Care Support Services Toronto Central (an organisation that provides home care through the public healthcare system).

PEACH was conceived and founded by palliative care physician Dr Naheed Dosani in 2014. Initially PEACH started with one physician and one nurse. Over time, driven by Dr Dosani's vision, the scope of work has increased, and the multi-disciplinary team has expanded to now consist of a group of palliative care physicians, a psychiatrist, a health navigator, nurse coordinator, a peer worker and home care coordinator. The team geographically covers the entire City of Toronto, assessing and supporting patients in community settings including shelters and transitional housing.

Box Three. Palliative Education And Care for the Homeless (PEACH), Toronto, Ontario, Canada (Continued)

PEACH is driven by the core values of:[68]

- Harm reduction
- **Trauma-informed** care
- Intersectionality and anti-oppression
- Interprofessional approach to care

PEACH is flexible, responsive, has a low barrier to referral, and can also provide care for uninsured patients. PEACH has a network of relationships throughout the local health and social care sector, meaning the team can connect and effectively advocate for patients with other services to meet the complex and diverse needs of patients.

PEACH is recognised both in Canada and internationally as an initiative demonstrating best practice in equitable access to palliative care.

Box Four. Dr Naheed Dosani, Founder & Lead, PEACH Programme says:

"The PEACH program functions at the critical intersection of palliative care & social justice, working to address the profound healthcare inequities faced by individuals experiencing homelessness. Our mobile, street- and shelter-based model is designed to meet people wherever they are at, ensuring that no one falls through the cracks during their most vulnerable moments. By integrating medical, social, and housing services, we not only provide compassionate, **trauma-informed** care but also address the **social determinants of health** that significantly impact well-being and survival. Through our work with the PEACH Program, we strive to ensure that every individual has access to the dignity, respect, and comprehensive support they deserve at the end of life, while challenging the systemic barriers that often exclude **structurally vulnerable** populations from receiving the kind of care they deserve".

Perseverance

Inclusive approaches are unlikely to be straightforward and can even be messy. People experiencing marginalisation who have experienced significant past trauma may be suspicious and unlikely to be open about personal details of their life straightaway. Building trust takes time and perseverance. We need to be willing to show that we are persistent, safe people motivated by a desire to care, and are not going to abandon the people we care for. Showing this requires perseverance.

We should prepare for the unexpected and also inefficiency. Things will not always go the way we plan for. This includes accepting sometimes consultations don't work out the first time, the

second time, or even the tenth time when we try to gather information from a patient. Patient assessments may need to occur over a period of time. Inevitably, we should be prepared to provide more regular contact and spend more time than we do for other patients, to build up relationships and accommodate the needs of people experiencing marginalisation.

Conclusions

Palliative care should be initiated early to achieve the best outcomes. Despite this, for marginalised patients, palliative care is often offered too late or not at all. During my research, I identified other models of care which demonstrate good practice for people experiencing marginalisation – through early contact and persistency.

I observed in these cases that there was palliative care involvement at a relatively early stage of the patient **trajectory** (**specialist palliative care** input at an earlier stage than I have observed in the UK). I believe palliative care in the UK can reduce the barriers to access through new ways of working. In developing such new ways, we should focus on early contact, proactive engagement, low barriers to referral and acceptance, meeting patients where they are, and perseverance.

Recommendation Two: Peer-to-peer care and support

Palliative care for people experiencing marginalisation should include and be guided by people from within the same marginalised community. Peer-to-peer support or peer-to-peer care workers can increase patients' comfort and trust in palliative care and facilitate effective advocacy for patients.

"Many patients don't have the language to express the trauma they have experienced in their life. Part of our role is to help them put their feelings into words"

Trust

People who have experienced significant **trauma** may find it difficult to trust. Some patients may be used to environments where it is necessary to be distrustful. For people experiencing homelessness or who are in prison, it is reasonable for them to be on their guard.

People who have experienced **trauma** may be fearful of others who are perceived or presented as authoritative, due to previous experiences such as over-policing, criminalisation, or institutionalised racism and discrimination facilitated by people in authority. This lack of trust can also extend to healthcare professionals. We must remember that past trauma may stem from experiences with medicine and healthcare. Care can be traumatising, including care for people with life-limiting conditions (see Page 43).

In contrast, when care is provided for patients by their peers it may be easier to build trust between patient and carer. This approach is put into effect by the **Californian Medical Facility**

(CMF) Prison Hospice (Box Five, below). The CMF hospice adopts a model of peer-to-peer care – where incarcerated men are employed to provide care for other incarcerated men.

The patient knows that the person caring for him knows what it is like to be in prison. They may have similar past experiences, including traumatic experiences involving authority figures or experiences from within prison. Because of this, the patient may feel less of a barrier between himself and his carer. Patients may confide information that they had not told the doctors or nurses, and ultimately build a more trusting relationship than is possible with other healthcare providers.

Box Five. California Medical Facility Hospice, Vacaville, California, USA

The California Medical Facility (CMF) is a medium security men's prison in California, housing approx. 2,400 incarcerated people. CMF has a 17-bed inpatient hospice in which end-of-life care is delivered to those who need it. The development of the hospice was driven by Chaplain Keith Knauf. Originally, the hospice was started for the care of people dying due to AIDS complications in prison. More recently, the hospice is open to all incarcerated men there who need care at the end of their lives, regardless of diagnosis. The hospice is staffed by a team including healthcare professionals, Chaplain Keith, correctional officers, and peer care workers. Through this model, people who are incarcerated can be recruited to provide care for their peers and become integrated into the multi-disciplinary team.

The team aim to purposefully match a peer worker to each patient, e.g., matching those with similar interests and life experiences. For patients they do not already know well, or for those who are now unable to communicate, the team still take time to try to find out about the patient's life and interests. This allows more trust to develop between vulnerable patients and their carers, compared to if their carer was not a fellow incarcerated person. Peer carers know the lived experiences of incarceration. They may also have experienced similar adverse life events. These similar experiences provide interconnectedness. In this role, peer care workers also advocate for the needs of the patients, in communication with the healthcare and prison staff.

One of the policies of the hospice is that no prisoner dies alone. Peer workers maintain a 24/7 vigil for patients who are imminently dying.

The work of the hospice provides a paradigm shift for all involved: in this setting, correctional officers work alongside incarcerated people as colleagues. The hospice nurtures a non-toxic, healthy environment, where people take notice of one another. There is a network of support among one another, including providing pastoral support and bereavement care for each other within the entire team.

Empowerment

In all palliative care endeavours, we should view the patient as a whole person, encompassing their psychological, social, and spiritual experiences, and what quality of life means to them. In taking **trauma-informed** and inclusive approaches, we must go further and be conscious of power imbalances, working towards empowering marginalised people. Patients must be given a voice to tell us who they are and what matters to them. Peer-to-peer care and support can have a role in that empowerment. People who are marginalised may not have been able to put into words what matters to them, or express trauma that they are experiencing now or in their past. Peer carers who come from a similar background and have shared experiences can help empower the patient to find their voice.

Furthermore, peer carers have a role in advocating for the needs of patients. Those affected by life-threatening illness may not have the capacity to advocate themselves, but their carers can. This can take the form of the peer carer advocating for medical and nursing attention, reviews of medication, for information to explained in an accessible way, and, when needed, advocating for general improvement in the care of the patient.

Additionally, peer workers can work more broadly with organisations to advocate for inclusive care. This is demonstrated by the **Inuit Task Force (ITF) at The Oaks**, Ottawa, Canada, a residential facility specialising in providing a Managed Alcohol Programme. Many residents at the Oaks are Inuit, and the ITF have successfully influenced the organisation to be more inclusive and culturally safe for Inuit residents (see Box Six, below). In palliative care, we should recognise people with the same experiences and background as our marginalised patients as a tremendous resource in improving standards of care and directing us to be more inclusive.

Box Six. Inuit Task Force at The Oaks, Ottawa, Ontario, Canada

The Oaks is a residential facility operated in partnership between the Shepherds of Good Hope and Ottawa Inner City Health. The majority of residents participate in the Managed Alcohol Programme – a harm reduction approach to help stabilise participants' alcohol dependence. Support for participants includes physical and mental health care, help with personal needs, daily meals, and life-skills training.

Over 40% of the Oaks residents are either First Nations or Inuit. The Inuit Task Force (ITF) was formed in order to offer peer-to-peer support for participants from peers with the same cultural and historical background. Benefits of the taskforce have included:

- Assisting Inuit people to access the service
- Supporting health literacy
- Developing Inuit language versions of medical questionnaires
- Advocating about how to better serve Inuit residents
- Serving *country food* – traditional food obtained from hunting, fishing, and gathering

In this case, Inuit peer workers were not formally employed by the organisation, as the participants felt this was culturally inappropriate, because helping one another is an accepted part of Inuit culture, without expectation of payment. The ITF are very proud of the work they do. See Page 67 for images of the ITF.

Rehabilitation

The meaning of rehabilitation varies in different contexts and may be considered in various ways for people experiencing types of marginalisation, e.g. we may consider rehabilitative or restorative approaches to "justice" for people in prison to assist them in ceasing ongoing involvement with the criminal justice system after release from prison.

Harm reduction (Page 72) is a term describing practices which aim to reduce the harms associated with substance use, without requiring that the person stops using substances as a precondition of support.

In contrast, rehabilitation can be used to mean recovery from addiction and eventual abstinence from substance use. Although rehabilitation is not a central focus of this report, for patients who wish to and are able to engage in rehabilitation, peer support is useful. For example, at the **Shattuck Cottage Community** in Boston, USA (Box Nine, Page 70, people experiencing homelessness have the opportunity to work with a drug peer worker who was previously homeless and addicted to substances. I learned that through this peer-to-peer support with someone who has had the same experiences, a person can see their own potential to change and start to imagine her/his life differently.

However, we must not expect rehabilitation and abstinence in palliative care for patients who do not wish this and especially for patients who are soon approaching the end of their lives. We should provide inclusive care for all patients, whether or not they are able to engage in rehabilitation at this point in their lives – therefore I mainly focus instead on harm reduction in this report. In Recommendation Four (Page 72), I go into more detail about integrating inclusive approaches to people who use substances through policies of harm reduction.

Recognition and value

Providing peer-to-peer care and support can also be beneficial to the marginalised people acting as peer carers and peer workers, and we should do what we can to enhance the benefit to the people in these peer support roles. There can be great satisfaction in working to improve the quality of life of one's peers – shown, for example, by the **Inuit Task Force** (Box Six, Page 64) who take pride in what they achieve for their peers. In another example from California, I observed people in prison who work as carers for fellow people in prison undertaking palliative care training as part of the **Humane Prison Hospice Project** (Box Eight, Page 66) and learned how rewarding and fulfilling this work was to them. Likewise, I learned from **Fernando Murillo** (Box Seven, Page 66), a formerly incarcerated person who worked as a peer carer in the California Medical Facility, about how transformative and deeply rewarding this work was for him while he was in prison.

As well as personal fulfilment, we should find ways to encourage, recognise, and reward the value of peer workers in palliative care. This can include through qualifications to recognise achievement, such as the incarcerated people trained as peer carers through the Humane Prison Hospice Project. I believe we should go further and recognise peer workers for what they are, effective and valuable members of the multi-disciplinary team. This recognition should occur through respectful working relationships, but also through employment and payment. Inclusive approaches involve consciously avoiding practices which exploit the labour of marginalised

Box Seven. Fernando Murillo (left) is an advocate for care of dying people in prison. Fernando was formerly incarcerated in the Californian prison system, and it was during his time at the California Medical Facility that he began work as a pastoral care worker at CMF prison hospice. Fernando told me that the work was emotionally and physically challenging, but also intensely rewarding. Dying in prison was not seen as a good outcome among the incarcerated people, and Fernando recounts that the work was like seeing a mirror held up to one's own face about what the future may potentially hold. However, peer-to-peer care gave Fernando and the other workers the opportunity to care for their most vulnerable peers, and make the dying process as comfortable as possible in that setting. Now in the community, Fernando helps others by putting into practice what he learned at his time working in the CMF hospice. Fernando works as an educator for the Humane Prison Hospice Project in California (Box Eight below). Fernando's advice for other prisons considering adopting a peer-to-peer palliative care model is that each prison has its own unique culture, history, and dynamics, therefore think carefully about what may work in each individual setting: there is no one-size-fits-all approach. Most of all, "remember that people are people 100% of the time." **Image copyright Fernando Murillo. Reproduced with permission**

Box Eight. Humane Prison Hospice Project, California, USA

The Humane Prison Hospice Project (commonly called simply 'Humane') is a non-profit organisation which provides education, advocacy, and training, driven by the value of compassionate end-of-life care as a right for people in prison. Through Humane's model, incarcerated individuals are supported to provide end-of-life care for their peers. Humane originated as a group of passionate individuals starting to work with incarcerated people in San Quentin Rehabilitation Center (formerly San Quentin Prison), California. Humane provided Compassionate End-of-Life Training for members of the peer crisis support team, Brothers' Keepers. Since then, Humane have been active in advocating for the needs of people aging and dying in prison more widely. Due to their expertise, Humane were invited to develop a curriculum for peer-to-peer end-of-life care by a palliative care physician in the California Correctional Healthcare Services who holds responsibility for healthcare services for the incarcerated population in California: developing a programme to educate palliative and hospice peer workers across California prisons. The Palliative Care Peer Support Training curriculum Humane have developed comprehensively covers topics including communication and listening skills, cultural competency, healthcare paperwork, equipment, and understanding grief and loss. Thus far, Humane's training programme has been delivered to peer workers in two prisons – California Medical Facility and Central California Women's Facility. The training has been hugely well received and recognised as equipping new carers with the necessary skills to provide palliative and end-of-life care for their peers. Humane is currently planning to scale their work, by implementing their training across other California prisons and nationally, seeking to reach prisons in other US states also. https://humaneprisonhospiceproject.org/

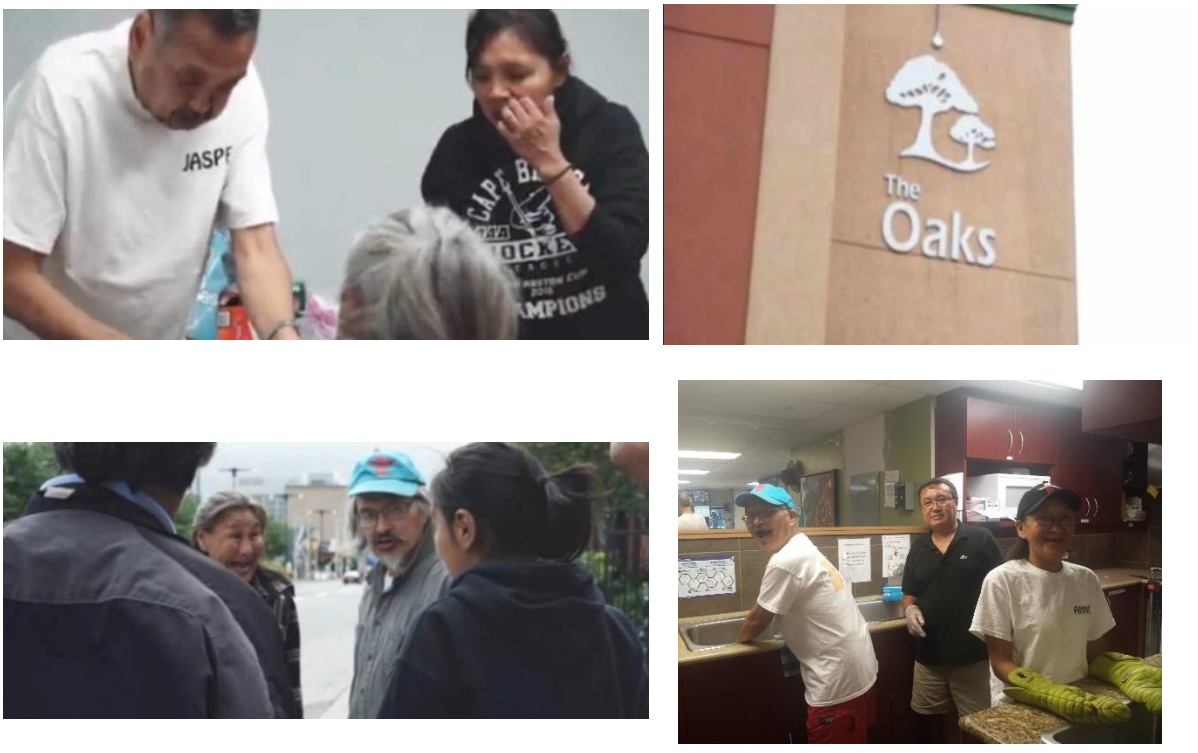
humane
PRISON HOSPICE PROJECT

people – therefore palliative care services and organisations which include peer workers should provide payment for their contribution.

Conclusions

Palliative care of patients experiencing marginalisation should include care and support from people with similar lived experiences to the patients. By including this peer-to-peer care, palliative care can be more inclusive and **trauma-informed**, especially through improving patient trust in their carers and by empowering the patient. There are also benefits to the marginalised people providing the care, and we should recognise their contribution to the team, including through payment.

In adopting peer-to-peer care, we will likely see long-standing barriers and hierarchies begin to reduce or break down. People who have the same lived experience as our marginalised patients – for reasons such as drug use, homelessness or imprisonment – will be seen less as people "other" than us and more as colleagues. I believe such changes can have a positive influence on the culture and mindset of the whole team, and ultimately lead to achieving better palliative care for our patients.



Above: The Inuit Task Force at The Oaks, Ottawa, Canada (Box Six, Page 64). Images copyright Ottawa Inner City Health Inc. Reproduced with permission.

Recommendation Three: Prioritise housing as healthcare

Homelessness leads to worse health outcomes and increased mortality. Housing is therefore a vital component of healthcare. Housing First is the approach of offering housing to homeless people as quickly as possible, without pre-requisites, combined with holistic, trauma-informed attitudes. In palliative care, we should take a holistic approach to fulfilling the patient's needs and improving quality of life, and for people experiencing homelessness this should include a Housing First approach.

Lack of housing leads to negative outcomes

Most of what makes people sick is not related to genetics or personal choices but the conditions in which they live. The term **social determinants of health** is used to refer to factors outside of biology and lifestyle choices that influence or determine our health. **Social determinants of health** include education, food security, violence and issues of social inclusion and discrimination. The effect of **social determinants of health** can be seen in the social gradient in health within countries – the most privileged people tending to keep in the best health, and the most disadvantaged keeping in the poorest health.[70]

Housing is a hugely important **social determinant of health**: homelessness leads to bad outcomes in health and access to end-of-life care. I have defined homelessness as a concept encompassing everyone who does not have a suitable place to live including a range from those who are at risk of eviction, those insecurely housed, those in shelters, and those sleeping on the street (Page 25). Many of the most marginalised experience homelessness for at least some of their lives. There is a large overlap between homelessness and other **structural vulnerabilities**, e.g. many people experience all three of the core forms of severe disadvantage: homelessness, drug use, and contact with the criminal justice system.[27]

Housing is healthcare

On Page 26 I provided detail about the poorer health outcomes for people experiencing homelessness, including increased risk of mental and physical illness, and far reduced life expectancy compared to the general population. People across the spectrum of homelessness are at increased risk of health complications, i.e. not only those who are sleeping rough.[31] People who are homeless are at risk from sudden death from violence, poisoning, and suicide. They are also at risk of frailty and chronic diseases including cancer, chronic infections and organ failure. I consider homelessness to be a life-limiting condition.

The vital importance of housing cannot be separated from the vital importance of healthcare. Poor health puts a person at risk of being homeless. Homelessness causes poor health, reduces life expectancy, exacerbates existing conditions and reduces ability to engage with treatment for health problems. Housing and healthcare are essential and interconnected.[71]

It is clear that providing housing is a healthcare intervention. Although homelessness is life-limiting, it is not an irrevocable condition. **Structural vulnerabilities**, including homelessness, are not static, and may be changeable. Whenever any person, from across the public or charity

sectors, provides housing for a homeless person they are not only improving someone's quality of life and wellbeing but reducing that person's risk of illness. **Put simply: providing housing is healthcare**.

Housing First

Housing First describes the concept of offering housing to homeless people as quickly as possible, without conditions. **Housing First** is generally combined with holistic, **trauma-informed** attitudes.

For example, abstinence from drugs or alcohol should not be required in order for a person to be housed. There should not be a question "is this person *ready* for housing"? The aim is for homeless people to be rapidly moved directly from the streets or shelters to their own accommodation, bypassing temporary homeless accommodation.[71,72]

Housing First evolved from social activist movements, particularly from activism for improved outcomes for people living with HIV/AIDS and has developed into policies which have been adopted in various countries. **Housing First** is founded on the basis that housing is a universal human right. It recognises the deleterious effects of homelessness on a person's well-being which must be urgently addressed. Although we must not ignore the systemic, historical, and political factors that lead to a person being homeless, the **immediate priority** for homeless individuals is to provide housing.[71] **Housing First** has been found to be a cost effective in settings where it has been implemented.[73]

In Scotland, **Housing First** has been endorsed by the Scottish Government and adopted in policy. At least 26 of Scotland's 32 local authorities are delivering **Housing First**. **Housing First** in Scotland also offers supportive services, but housing security does not depend on the individual's engagement with these support services.[74]

Housing promotes recovery from existing illness and reduces risk of developing new illnesses. This includes through housing facilitating:[73]

- personal hygiene (including wound care and dressing changes)
- medication storage
- protection from traumatic experiences encountered on the street including violence or the threat of violence
- establishment of stable personal relationships
- reduced risky sexual behaviours
- interaction with healthcare providers and social support systems
- increased engagement with treatment plans
- regular meals
- being able to keep appointments
- reduced anxiety and stress-related illnesses
- stable and/or reduced substance use

During my fellowship, I have observed interventions which incorporate the concept of **Housing First** having a profound impact on improving the life **trajectory** of people experiencing homelessness. For example, the **Shattuck Cottage Community**, operated by **Commonwealth Care Alliance** in Boston, USA, was born out of the need to provide emergency housing for people

living in homeless encampments in Boston (See Box Nine, below). The community provides an environment of safety and stability, gives individuals access to healthcare, and provides them with the pathway they need to find permanent housing.

Box Nine. The Shattuck Cottage Community, Boston, Massachusetts, USA

The Shattuck Cottages is an innovative, low-threshold temporary housing facility for chronically homeless individuals, operated by Commonwealth Care Alliance (see Box Two, Page 59) in partnership with the Commonwealth of Massachusetts and the City of Boston. The community was established to provide a solution to the problems faced by people experiencing addictions and homelessness in Boston, many previously living in encampments.

The community consists of 18 pre-fabricated cabins. Residents who were previously experiencing street homelessness now have a secure and private place to sleep and store their belongings. Abstinence from drugs or alcohol are not required to be able to obtain residency in the cottages. The community provides residents with a range of services including nursing care, harm reduction tools like clean needles and safe sharps disposal units, peer counselling, substance use recovery coaching, and a pathway to permanent housing.

The Shattuck Cottage Community programme has led to residents, including those who have previously been homeless for years or decades, successfully moving on to be placed in secure housing. At the time of my research, the project had so far placed 81 residents into permanent housing. Due to these successes, there are plans for this model to be replicated across Massachusetts.

Such transformative change is also demonstrated at the **Diane Morrison Hospice**, in Ottawa, Canada (see Box Twelve, Page 75). This hospice provides palliative care for patients who are homeless, including providing a place for patients to receive end-of-life care when needed. However, the stability given to homeless people in this environment can allow the patient's condition to recover, leading to them no longer experiencing an immediately life-threatening condition, and being well enough to move into secure and permanent housing. This illustrates the principle that providing housing can be life-extending and life-saving.

Housing is palliative care

Providing housing may be the sufficient healthcare "treatment" to meet the needs for some homeless people. For others – those who people who are homeless and also have another life-limiting condition – palliative care is needed and must be delivered in a way which incorporates the principles of housing as healthcare. The **Housing First** principle of rapid housing based on need fits well with the aim of palliative care: to holistically meet the needs of patients, intervening to improve quality-of-life for the patient's remaining time.

Palliative care organisations, local authorities responsible for housing, and other organisations working with homeless people should work together to provide housing for people with life-limiting conditions. There must be attention given to the fact that the person's health and function is likely to continue to deteriorate as the underlying condition progresses. We must be able to

provide housing which is suitable and adaptable for the care needs of people with life-limiting illnesses, especially as they go through a process of change.

The **Palliative Outreach Resource Team (PORT)** in Victoria, Canda (Box Ten, below) exemplify the integration between palliative care and social care systems leading to good outcomes for the patient. They have partnered with local shelter system to provide accommodation specifically for homeless people who have life-limiting conditions who have been identified and referred by PORT. These palliative care shelter rooms provide a stable home, and a space for medical equipment (e.g. hospital bed) and where health workers can visit and provide care. Good relationships between the palliative care team, PORT, and the homeless sector have allowed this programme to be developed by sharing learning with one another and working together to develop solutions.

We should learn from this model and consider how it can best be adapted. Could a similar integrated model between palliative care and housing be adopted in the UK? Ideally this would follow the principle of **Housing First** – giving the homeless person the opportunity to be housed indefinitely in stable accommodation, bypassing transitional accommodation or shelter settings. PORT's model also does not currently facilitate care at the very end-of-life in the accommodation provided, and the patient would need transferred to another setting to receive care in the final days of life. Choice at the end-of-life including dying in the place of one's own is held as an aspiration of good end-of-life care. This includes giving patients the choice to die at home. When developing UK models of palliative and end-of-life care in housing, we should consider accommodation which could be a suitable site for the person to receive community-based care while dying, if the person chooses.

Box Ten. Palliative Outreach Resource Team (PORT),Victoria, British Columbia, Canada

PORT is an initiative collaboratively operated by the University of Victoria, Island Health, and Victoria Cool Aid Society. The PORT team includes physicians, a nurse coordinator, and outreach worker, whose roles include working with **structurally vulnerable** people to create advance care plans and have their wishes respected, and facilitating end-of-life care for people who are homeless or vulnerably housed. PORT aims to connect people with life-limiting illness and their caregivers to palliative care and other health and social support systems, especially for individuals who may otherwise face barriers to getting the help they need.

In partnership with PORT, the emergency and transitional housing shelter Rock Bay Shelter in Victoria provides transitional housing for homeless people who have a life-limiting illness and whose condition is generally deteriorating. This arrangement provides the patient with their own secure room and bathroom, separate from the main shelter beds. Although the shelter staff are not clinically trained, healthcare professionals can visit patients in this setting. Patients have access to meals and designated safe drug consumption areas . This arrangement provides much needed housing for individuals, at a heavily subsidised fee, for people who would otherwise be facing the dual challenges of deteriorating health and homelessness. In this model, it is intended that when the patient reaches the very end of their life and requires regular nursing and medical care, they would transfer to a hospital or hospice.

Conclusions

For people experiencing homelessness and an additional life-limiting condition, palliative care must consider the **social determinants of health** and work towards patients with life-limiting conditions being securely housed as smoothly as possible. We should incorporate the principle of **Housing First**.

This leads me to pose the question: **can our UK systems adapt to allow palliative care providers to prescribe housing as a palliative care intervention?**

Palliative care teams and organisations should foster close collaborative relationships with social housing authorities and organisations working with the homeless and consider how we can integrate our care with each other. Housing provided should be suitable and adaptable for the care needs of people with life-limiting illnesses and be an optional place of care for patients who wish to receive their end of life care at home.

Beyond the individual level, we must consider our responsibilities at the social and systemic level. For health **equity** to be achieved, the **social determinants of health** must be addressed. Advocating for policies and practice which will distribute adequate and safe housing to all who need it should very much be the concern of health care and (perhaps especially) palliative care professionals and organisations.

Recommendation Four: Adopt a harm reduction approach to substance use

People who use substances including alcohol or other drugs often experience marginalisation and criminalisation. Systems and settings which require abstinence from substance use may repel patients and result in difficulty maintaining a trusting therapeutic relationship. In contrast, an approach which acknowledges substance use while aiming to reduce its harms can help to ameliorate these challenges and increase accessibility of palliative care.

What is harm reduction?

"[..] Policies, programmes and practices that aim to minimise the negative health, social and legal impacts associated with drug use, drug policies and drug laws. Harm reduction is grounded in justice and human rights. It focuses on positive change and on working with people without judgment, coercion, discrimination, or requiring that people stop using drugs as a precondition of support" Harm Reduction International 2022[75]

Harm reduction is essential

This recommendation focuses on adopting a harm reduction approach (defined above) as part of inclusive palliative care for people experiencing marginalisation. Taking a harm reduction approach does not mean that we deny that alcohol and drugs can cause our patients harm. On

the contrary, a harm reduction approach means we are aware of the potential for harm and want to do what we can to reduce those harms for people who use substances. Vitally, this includes preventing overdose deaths.

Harm reduction approaches are especially important for people experiencing marginalisation. There is significant overlap with marginalised groups. Many experiencing homelessness are also people who use drugs (**PWUD**). Those most likely to experience serious harm related to substance use are often those who have **structural vulnerabilities** including homelessness, social deprivation, or come from a racialised minority. These marginalised groups are also most likely to experience criminalisation and stigmatisation because of alcohol and drug use compared to those more privileged.[75]

Types of harm reduction approach

Harm reduction encompasses all policies and practices aimed to reduce the harms caused by substances. Harm reduction approaches can include:[76,77]

- Naloxone supply and availability – medication to reverse the effects of heroin and other opioids, which can prevent deaths from opioid overdose if given promptly
- Managed Alcohol Programmes (MAPs) – a safer consumption approach for people living with alcohol dependency which provides people with regular prescribed doses of alcohol (see **The Oaks**, Box Six, Page 64, and **Diane Morrison Hospice**, Box Twelve, Page 75)
- Safer supply – prescription and supply of drugs which are legally manufactured and have known content and potency, as an alternative to drugs available on the illegal drug market
- Opioid Substitution Therapy (OST) – administering a prescribed dosage of opioid medicines (e.g. methadone or buprenorphine) to patients with opioid dependence to reduce harms associated with taking non-prescribed or street-obtained opioids
- Supervised drug consumption programmes (also known as safer consumption) – designated sites where people can use pre-obtained drugs under the safety and support of trained personnel [Harm Reduction.org] (see **The "Trailer"**, Box Eleven, below)
- Drug checking (also known as drug safety testing) – a harm reduction approach which involves analysing substances of concern to provide people with information on the substance's content and potency (see **Substance Drug Checking**, Box Thirteen, Page 76)

Harm reduction approaches including supervised drug consumption programmes are established in some cities in North America to tackle the opioid drug poisoning crisis. I had the opportunity to visit and learn from one such programme, **The "Trailer"**, in Ottawa, Canada (see Box Eleven, below).

Box Eleven. Consumption and Treatment Service ("The Trailer"),Ottawa, Ontario, Canada

The Trailer aims to reduce the negative consequences of overdoses and unstable drug supply by providing a supervised consumption site in downtown Ottawa. This 24/7 service provides 14 individual booths in which clients can attend with their own supply of drugs for injection or oral consumption under the supervision of nursing staff. Clients are allocated a code for their records and do not need to provide their real name. Healthcare staff maintain constant surveillance, ready to provide naloxone if needed, and, if it becomes necessary, to call emergency services. services including access to primary care, mental health care, a safer supply program, and substance use treatment. Case managers working within the Trailer

Box Eleven. Consumption and Treatment Service ("The Trailer"),Ottawa, Ontario, Canada (continued)

The Trailer receives 7000 visits from clients per month. In 2023, the trailer team reversed over 1300 overdoses. In addition to supervision of people while they use drugs, the Trailer provides a range of other services including access to primary care, mental health care, a safer supply program, and substance use treatment. Case managers working within the Trailer work with clients to reach goals and access treatment and other services as needed. The Trailer receives 7000 visits from clients per month. In 2023, the trailer team reversed over 1300 overdoses.

Harm reduction work ongoing – examples from Scotland

"The war on drugs is over. No-one won and the main casualties were not organised criminals but the poorest and most vulnerable"

- Elena Whitham MSP, Minister for drugs and alcohol policy (Scottish Government)[79]

Safer consumption programmes have been introduced in some areas of Scotland, e.g. the Managed Alcohol Programme run by the Simon Community Scotland, for men experiencing homelessness and alcohol dependency in Glasgow.[79] Glasgow City Health and Social Care Partnership and NHS Greater Glasgow and Clyde have announced the opening of a Safer Drug Consumption Facility (SDCF) in Glasgow to provide a supervised healthcare setting where people can inject drugs, obtained elsewhere, in the presence of trained health and social care professionals, using sterile injecting equipment.

The SDCF will also facilitate people who attend to access other services such as primary care, and necessary assessments for welfare benefits and housing.[80] Scotland's senior law officer has agreed that people will not be prosecuted for the possession of drugs within the SDCF.[79]

So far, such approaches are limited only to those in the localities of these initiatives and to those who meet the eligibility criteria. However, they demonstrate that there is an appetite in Scotland to make a positive difference for **PWUD**, and that there is capacity to innovate in this area.

Harm reduction in palliative care

In the UK, I have so far not worked in or been aware of a palliative care environment where there has been an explicit harm reduction policy. Like mainstream healthcare, hospice in-patient units have a general implied or explicit expectation that the patient be abstinent, while on the premises, from drugs which are not prescribed.

This is despite the high level of palliative care need and reduced life expectancy among people experiencing marginalisation (many of whom are **PWUD**). Such abstinence-focused approaches may alienate **PWUD**. **PWUD** may be fearful of engaging with abstinence-focused services because of fear of stigmatisation, criminalisation, or going into substance withdrawal. There may

be a very reasonable feeling of having to choose between going into withdrawal or going without palliative care.

During my Fellowship I had the opportunity to observe palliative care teams and organisations which integrated harm reduction principles. **The Diane Morrison Hospice** is one such palliative care organisation (see Box Twelve, below). This specialist hospice in Ottawa, Canada, provides care for people who are homeless. Their harm reduction approach includes a Managed Alcohol Programme and prescription of Opioid Substitution Therapy. The hospice team view these as important components of the holistic palliative care they provide for their patients and allows them to be as inclusive as possible for their marginalised patients.

Box Twelve. The Ottawa Mission Hospice: Diane Morrison Hospice, Ottawa, Ontario, Canada

The Diane Morrison Hospice is operated in collaboration between Ottawa Inner City Health and The Ottawa Mission, a charitable organisation which provides shelter, food, clothing, job training, and spiritual support to people who are homeless. The hospice opened in 2001 to meet the unique palliative care needs of members of people experiencing homelessness, especially at a time when the AIDS crisis was devastating the community. The pioneering hospice was designed to allow people who were homeless and dying from AIDS to avoid hospitalisation and be cared for within the shelter community.

Over time, the hospice has expanded from its initial 6-beds to 21 beds. Due to advances in HIV treatment, the number of deaths from AIDS has reduced, and the Diane Morrison Hospice has moved its primary focus from the needs of people with AIDS to palliative care needs of people who are homeless affected by contemporary life-limiting conditions including addictions, cancer, and organ failure. The hospice is guided by the core principle of unconditional acceptance to people who are homeless by providing palliative care for their needs. This acceptance is based on mercy, compassion, safety, warmth and comfort.

The team has a variety of skills and expertise, including an understanding of people living with trauma, serious mental illness, and addictions. The team work to relieve pain and treat addiction. Care for patients includes a Managed Alcohol Programme (sharing resources, by utilising wine brewed at The Oaks – see Box Six, Page 64), and a Managed Opioid Programme, providing prescribed opioid agonist substitution treatment for patients living with opioid dependency.

Although the Diane Morrison Hospice provides care for people at the very end of life, it also supports patients who are in the last years and months of life. The team help to connect with patients' families, assist with burials and cremations, and help patients with tasks such as money management. Furthermore, the comprehensive palliative care including adequate nutrition and psychosocial support, can itself be life extending. People who were very ill may regain sufficient health to return to living where they were previously or in a new home which meets their needs.

As we observe the acceptability and effectiveness of UK harm reduction approaches (like the new SDCF described above), I hope to see these approaches integrated into palliative care practice. At present, I believe there would be significant concern about integrating approaches like safer drug consumption or safer supply in **specialist palliative care** UK, including concerns about

legal repercussions for patients and staff. It may be some time before these concerns are ameliorated and before we could see a hospice setting able to accommodate supervised consumption of non-prescribed drugs for **PWUD**.

However, I hope we can see closer working between people working in palliative care and in harm reduction. For example, we could offer palliative care outreach into established safer consumption or drug checking sites. We should foster clear lines of communication and bi-directional referral processes between palliative care providers and people working in harm reduction to faciliate patients getting access to the care and support services they need.

It may also be achievable to initiate Managed Alcohol Programmes and Opioid Substitution Therapy in **specialist palliative care** settings, as Diane Morrison Hospice in Ottawa do. These harm reduction approaches can play a role in making these settings more accessible and satisfactory to many people experiencing marginalisation including homelessness.

Box Thirteen. Substance Drug Checking, Canadian Institute for Substance Use Research, University of Victoria, British Columbia, Canada

Substance Drug Checking offers a free, confidential drug checking programme in Victoria. The programme consists of multiple drug checking instruments to determine a sample's composition and concentration of main active ingredients, fillers, cutting agents, and unexpected drugs including the presence of fentanyls.

Their drug checking technologies includes test strips, Fourier transform infra-red spectroscopy, Raman spectroscopy, and Paper-Spray mass spectrometry. In-person services and results can be provided directly within 15-20 minutes.

Substance Drug Checking makes efforts to be accessible to those who live rurally and those who are unlikely or unable to access harm reduction services personally: they offer third-party drug checking (i.e. on behalf of others), a distributed drug checking model across Vancouver Island, and samples can be submitted by mail. Substance Drug Checking also offer drug checking services at local events and festivals. Through their comprehensive, distributed approach to drug checking, Substance Drug Checking aims for increased power and accountability within the drugs market, more accurate public health monitoring and reporting, and better-informed drug policy implementation.

Conclusions

Harm reduction is vital for care of people experiencing marginalisation, as their worse health outcomes often include harms presented by substance use and risk of overdoses. Furthermore, acknowledging and accommodating the lifestyles of our patients should be part of the holistic approach of palliative care, and will make palliative care more accessible and inclusive, without mandating abstinence. The examples discussed show that it is possible to put harm reduction principles into practice, and it is heartening to see that developments are afoot in the UK, working within the confines of the law.

I believe a more inclusive future for palliative care must include harm reduction approaches. Incorporating Managed Alcohol and Opioid Substitution Therapy into palliative care provision for palliative care for people experiencing marginalisation may be achievable. Beyond that, we must

consider how we position ourselves and interact with approaches like safer consumption and safer supply within our legal frameworks and duty to patient care, in co-operation with the police and with harm reduction professionals.

Recommendation Five: Embed mental health care

Many people experiencing marginalisation have experienced trauma, and a significant proportion will also have a Severe and Persistent Mental Illness. Inclusive and trauma-informed approaches to palliative care should therefore facilitate and embed mental health care in their structure.

The need for embedded mental health care

The current standard of palliative and end-of-life care is inadequate for people who develop a life-limiting illness while living with mental illness. The vital need for improved practice here is an extensive and complex topic deserving of thorough research and a separate report in its own right. People with mental illness are vulnerable and are a marginalised patient group. In my research, I did not focus specifically on people with mental illness, and I am not able in this report to provide justice to the discussion of challenges and potential solutions these patients deserve.

Nevertheless, mental health care is relevant to the topic of this report – palliative and end-of-life care for people experiencing marginalisation – as I learned during my research. Many people experiencing marginalisation for other reasons including homelessness or imprisonment also experience mental illness, which can bring another layer of **structural vulnerability**. It is important I shine a light on these issues, while acknowledging future work should go further than I am able to here.

This recommendation focuses on finding ways to embed mental health care into inclusive palliative care approaches for people experiencing marginalisation. The need for better co-ordination between mental health care and palliative care has been recognised, but currently in the UK these types of care are normally provided by services which are very divided.

Despite these practical divisions, there are many similarities in philosophy and approach between mental health care and palliative care:[81]

- both are person-centred
- both are focused on the therapeutic relationship
- both should be centred on compassionate and holistic care
- both champion respect for autonomy and quality of life as defined by the person receiving care
- lack of familiarity with mental health care or palliative care can lead to misunderstandings, stigma, and emotional distress, providing barriers to care

Like palliative care, those working in mental health care have also recognised the need to be **trauma-informed** given the high proportion of people with mental illnesses who have experienced significant **trauma** (much greater than the general population).[5]

Mental health care and trauma

In this report, I have made clear that inclusive palliative care approaches must be **trauma-informed**. However, we must differentiate between:

- being **trauma-informed** (something we should all be doing, regardless of whether we know our patients have a confirmed experience(s) of **trauma**)
- offering specific treatment or care for psychological trauma (which should only be done by mental health professionals with the right skills and training, for patients with known experience(s) of **trauma**)

I hope all individuals and organisations working with people experiencing marginalisation are or will become **trauma-informed** in approach, but it is not possible or safe for them to all offer trauma-specific supports.

Trauma-specific supports are provided by trained mental health professionals specifically when the individual has a known history of trauma, providing interventions which directly treat its psychological effects. In their National Scottish Framework for transforming psychological trauma, NHS Education for Scotland make this distinction by defining different tiers of practice for the Scottish workforce:[4]

- **Trauma-Informed**
  A basic level for trauma informed practice that should be relevant to all workers regardless of role
- **Trauma skilled**
  A level of knowledge and skills required for those who have more direct and substantial contact with individuals who may be affected by traumatic events, whether or not the trauma is known about
- **Trauma enhanced**
  A level of knowledge and skills required by staff who have more regular and intense contact with individual who are known to be affected by traumatic events and who provide specific supports or interventions and/or who direct or manage services
- **Trauma specialist**
  A level of knowledge and skills required by staff who, by virtue of their role, training and practice setting, play a specialist role in directly providing evidence based psychological therapies to individuals affected by traumatic events

Using the words of this framework, this report **does not** advocate for palliative care workers to routinely become trauma specialists - nor should we be attempting to provide treatment for trauma without the adequate training, qualifications, and expertise. Psychotherapeutic treatment of trauma is beyond what I researched in this Fellowship.

However, as we work to become more **trauma-informed** in our approaches, I hope we can build stronger working relationships with mental health professionals and integrate with mental health care services. As part of our holistic approach to patients experiencing marginalisation, I hope

we can direct our patients affected by trauma to the accessible psychotherapeutic help that they need.

Mental illness and physical co-morbidities

Severe and Persistent Mental Illnesses (SPMIs) are those that are prolonged and recurrent, impair activities of daily living, and require long-term treatment.[82] Common **SPMIs** include schizophrenia, bipolar disorder, and major depression.[82] **SPMIs** in themselves are very disabling chronic illnesses, e.g. schizophrenia is the seventh leading cause of disability globally.[83]

People with **SPMI** suffer from more physical illnesses, greater severity of chronic disease, and late diagnosis of physical illness. From healthcare, people with **SPMIs** receive fewer diagnostic procedures, fewer medical and surgical interventions including chemotherapy for cancer, experience poor-quality care, die prematurely from physical illness, and may be less likely to receive palliative care and to be prescribed pain relief.[82] The worse health outcomes for people living with **SPMIs** results in a far reduced life expectancy compared to the general population. This phenomenon is referred to as the **Mortality Gap** (see Box Fourteen, below).[84,85]

Box Fourteen. The Mortality Gap

Severe mental disorders (including bipolar disorders and schizophrenia) are associated with poor health outcomes and high mortality rates. **The Mortality Gap** refers to the difference in life expectancy between people who have severe mental disorders and those who do not: in high-income countries people with severe mental disorders are expected to die 10 to 25 years earlier than the general population average. Despite improvements in healthcare, and general increases in life expectancy, the mortality gap has persisted over time. The worst levels of premature mortality can be found in those with mental disorders combined with substance use.[85,86]

Mental illness and palliative care

Despite the significant poor physical health outcomes for people living with **Severe and Persistent Mental Illnesses (SPMIs)** and reduced life expectancy, people living with SPMIs do not receive the same level of access to palliative care as people without an **SPMI**.[82] People with **SPMIs** often are not given the same opportunity to form anticipatory care plans which take into account their wishes as they reach the end of their lives.

This may result in greater use of emergency services in the last month of life, not having been given the opportunity to make a decision against cardiopulmonary resuscitation, and more invasive treatments rather than prioritising comfort at the end of life.[86]

Reasons why people with **SPMIs** do not receive adequate palliative and end-of-life care may include:[82,84,86,86]

- influence of psychiatric symptoms on a person's behaviours and healthcare-seeking or ability to engage in follow-up and continuity of care
- patients with **SPMI** may not report pain or may not express it in the way healthcare workers expect

- confusion among healthcare workers about the significance of physical symptoms, e.g. when unusual behaviours convey the presence of physical symptoms
- late diagnosis of life-limiting illness, resulting in high needs in a short time frame before patient death
- psychiatric symptoms may result in special care needs such as requiring quiet space or increased time for explanations and assessments
- family caregivers of people with **SPMI** may also have specific needs that can differ from those of other palliative patients
- people with **SPMI** at end-of-life are often transferred between settings, resulting in disruption of care
- limited or lack of communication between psychiatric services and palliative care services
- lack of training in palliative care and mental health care for those outside of mental health or palliative specialties
- lack of training in palliative care among mental health care workers
- lack of training in mental health care among palliative care workers
- people with **SPMIs** may lack social supports with people who could act as advocates or proxy decision makers
- there may be stigmatised and prejudiced attitudes among some health care workers
- influence of comorbid factors including poverty, lack of social support, and social isolation
- overlap with homelessness or imprisonment, and the associated barriers to care access that these **structural vulnerabilities** bring

People with mental illness have the right to the same high standard of palliative and end-of-life care as everyone else. This should include participating in anticipatory care planning. However, people living with **SPMIs** may not be given the opportunity, if healthcare workers assume they do not have the emotional competence or emotional fortitude.[83,86]

We must not assume that people with mental illness lack the mental capacity to make decisions about their palliative and end-of-life care. Although mental capacity to engage in these discussions may fluctuate, we should do what we can to promote autonomy, being flexible and engaging in conversations about end-of-life care planning at times when the patient has the maximal capacity to do so.

Embedding mental health care in palliative care for people experiencing marginalisation

Many people experiencing marginalisation suffer from mental illness, and mental illness provides additional barriers to them receiving the palliative and end-of-life care they need (as outlined above). For example, 45% people experiencing homelessness have a mental health condition, and 80% report having experienced symptoms of mental illness.[2]

People experiencing homelessness may suffer from the **tri-morbidity** of physical illness, mental illness, and drug use.[2] Incarcerated people who are suffering from **SPMI** and life-threatening illness are increasingly vulnerable to the harsh environment founds in prisons, where adequate pain and symptom management are often not provided.[82] So we can see that the need for improved palliative and end-of-life care for people with mental illnesses is vital.

People with **SPMI** may not seek medical attention in a timely manner or report early symptoms. In Recommendation One, I described the need for palliative care workers to make early, pro-active, and persistent contact with people experiencing marginalisation. Through this approach, I hope we can go some way to provide earlier interventions for people with **SPMIs**.

Moreover, poor communication and connection between systems of care can result in patients not getting the healthcare they need. We must consider how we can become integrated with mental health care services and practitioners. This must include good working relationships which facilitate palliative care input into mental health clinics, community teams, or in-patient settings. Conversely, in palliative care, we should strive to offer access to mental health care professionals as an embedded part of inclusive approaches.

During my fellowship I was able to observe an inclusive **trauma-informed** palliative care team, **PEACH** in Toronto (Box Three, Page 60, which included a psychiatrist as an integrated key team-member. The low barrier, outreach-based PEACH model of care allows **Dr Rosenbaum** to offer early intervention to patients who may not have accessed or engaged with mental health care otherwise. Furthermore, providing mental health care together with Health Navigator (social worker) support can facilitate a patient's engagement with other treatments and services (see Box Fifteen, below).

Box Fifteen. Dr Daniel Rosenbaum, Attending psychiatrist, Palliative Education and Care for the Homeless (PEACH) team

Dr Rosenbaum is a psychiatrist working with patients experiencing **structural vulnerabilities** and life-limiting illness as part of the community palliative care team, PEACH (Box Three, Page 60). Dr Rosenbaum took up this role due to his strong interest in **social determinants of health**, end-of-life care, and caring for patients with **Severe and Persistent Mental Illness (SPMI).** The patients with life-limiting conditions who are cared for by PEACH include those with **SPMI** and other patients who may benefit from a supportive, psychotherapeutic approach to help them cope with their illness and experience of **structural vulnerabilities**. Through working with PEACH, Dr Rosenbaum is able to provide reviews of patients who can benefit from psychiatric care in the community including shelters and community housing settings. The low barrier, outreach-based PEACH model of care allows Dr Rosenbaum to offer early intervention to patients who may not have accessed or engaged with mental health care otherwise. Furthermore, providing mental health care together with Health Navigator (social work) support can facilitate a patient's engagement with other treatments and services.

Conclusions

Inclusive palliative care approaches should be motivated to overcome the barriers to people with mental illness accessing the palliative and end-of-life care they need. People living with **SPMIs** are a marginalised patient group and mental illness is commonly found in people affected by other **structural vulnerabilities** including homelessness and imprisonment.

A major source of poor care accessibility for people living with mental illness is lack of training and awareness of other specialities and fragmentation between services. We should strive for good working relationships, fluidity of referrals – and, better yet, embedding mental health care into palliative care for marginalised people by including mental health care professionals as valued team members.

Recommendation Six: Utilise resources wisely

Trauma-informed and inclusive palliative care approaches require substantial resources. By building good relationships with colleagues across organisations and settings, we can strategically utilise or repurpose existing resources to reach patients more effectively, for the benefit of all.

Limited resources

In the United Kingdom healthcare including **specialist palliative care** is facing financial challenges. The funding for hospices generally operates outside of the provision for state funded healthcare meaning that hospice funding relies on charitable fundraising in order to function. The UK hospice sector faced a deficit of £77m in financial year 2023-24. This is mainly due to rising expenditure without statutory funding increasing in proportion.[87]

If mainstream healthcare, including palliative care, provision already faces such challenges, this begs the question of how we can hope to find the resources to go further and become more inclusive, in new, more expansive models of care. I recognise adopting the recommendations in this report will require significant re-organisation of how palliative care services operate. For example:

- **Recommendation One** – includes pro-actively seeking patients to provide palliative care, not waiting until they are referred into the system
- **Recommendation Two** – includes recruiting people who have the same lived experiences as our marginalised patients, and providing payment for their services
- **Recommendation Five** – includes working collaboratively with mental health care professionals, including integrating them into the palliative care team

I aim not to be prescriptive about how exactly these recommendations will be adopted, and recognise each service, team, or organisation needs to determine the best way to do this. Nevertheless, it is likely substantial resources will be required. We must be strategic about how we manage resources and consider the return on investment of resources.

Existing resources

We are unlikely to succeed in inclusive palliative care approaches without collaboration with existing teams, services and organisations who work with people experiencing marginalisation. Although systems are complicated and may be bureaucratic, we must strive for good working relationships, better communication, and low barriers between palliative care professionals and colleagues across systems, including social work, health care, addiction services, mental health, harm reduction, housing, prison, and shelter system colleagues.

Dynamic relationships will allow for easier identification by our colleagues of patients who would benefit from palliative care, and fluidity to allow us to promptly direct patients to services they need.

For example, **Palliative Education and Care for the Homeless (PEACH)** (Box Three, Page 60) provide palliative care for homeless people in Toronto, Canada, and achieve strong connections across care and social services to benefit their patients. All doctors on the PEACH team work directly for PEACH one day a week and work elsewhere in the health system on other days, meaning they can grow and maintain their network, and are easily able to interact with the system for the needs of patients.

Furthermore, inclusive palliative care services can involve integration within existing systems and organisations with shared goals. Due to the reduced quality of life and life expectancy of people experiencing homelessness and people who use drugs, high-quality, holistic care is likely to be of interest to both the shelter organisations and to palliative care providers. Likewise, working with palliative care is likely to be of interest in harm reduction workers for the welfare of their clients. Similarly, the prison population is ageing, with more people projected to die in prisons.[6] Therefore, prison staff should be interested in working with palliative care approaches.

The value of integration between systems is demonstrated by Ottawa Inner City Health, whose mission for helping people experiencing homelessness includes the combination of harm reduction with palliative care. For example, in the **Diane Morrison Hospice** (Box Twelve, Page 75). In their endeavours, Ottawa Inner City Health utilises existing resources to provide care to homeless people in Ottawa, exemplified by the **Targeted Engagement and Diversion (TED) programme** (Box Sixteen, below). The TED is based in the Shepherds of Good Hope shelter and involves health monitoring for people known to the shelter system affected by acute substance intoxication. This allows people who are affected to avoid being admitted to hospital and continue to be cared for within the shelter they are familiar with. This is a better use of resources than continually sending affected people to hospital, and more satisfactory to the shelter staff, paramedics, hospital team, and, most importantly, the patient.

In palliative care, we should learn from this principle and consider carefully how we can utilise existing resources to provide patients with the care they need, within the right system and in the location for the patient.

Box Sixteen. Ottawa Inner City Health Targeted Engagement and Diversion (TED) programme, Ottawa, Ontario, Canada

Ottawa Inner City Health Inc have integrated their Targeted Engagement and Diversion (TED) health care programme into the Temporary Enhanced Shelter Program (TESP) operated by Shepherds of Good Hope, a shelter in downtown Ottawa. The programme works with the ambulance service to facilitate diversion of patients from the acute hospitals to the TED programme as an alternative means of support for non-emergency issues related to chronic homelessness and addiction. For example, a person who is known within the shelter community and who is acutely intoxicated may be brought to TED rather than the hospital emergency department. There is a low barrier to access, and patients may also attend through self-referral, or rereferral from a friend, member of shelter staff, or police officer. TED programme provides accessible treatment and health care for people experiencing homelessness who have complex healthcare needs. TED can provide a 24-hour monitoring service for homeless people under the influence of drugs and alcohol which allows them to be safely cared for in the community, in a shelter setting, rather than in a hospital. The service includes monitoring equipment, observation rooms, medication, and resuscitation equipment, and is staffed by a team including nursing staff and nurse practitioners. Patients can receive supervised substance withdrawal in this programme – all within the shelter system.

Return on investment of resources

We know palliative care is valuable because of the benefits it brings to the lives of our patients and their loved ones – but furthermore, palliative care is resource saving. Palliative care prioritises quality of life, often resulting in patients deciding against medical and surgical interventions compared to patients who did not receive palliative care.

The emphasis on high quality care can be life-extending in some cases.[88] So, we can see that palliative care should not be viewed as a luxury, but as an essential component of healthcare. In fact, we cannot afford to go without palliative care. Sue Ryder estimated that without hospices, it would cost the UK government an additional £484 million each year to provide state-funded end-of-life care.[89]

In parallel, inclusive and harm reduction approaches (see Page 72) are essential and life-extending. For example, providing safer supply of opioid medication reduces overdoses and mortality from all causes.[77]

Looking at the bigger picture in the care of patients affected by marginalisation, a collaborative plan can allow anticipation of symptoms, avoidance of acute crises, and discussion of what the patient wants as they approach the end of their life. In contrast to the expense of resources that are used "firefighting" acute crises, a cohesive approach could allow for more reasonable resource expenditure, while providing clear benefit to the patient.

We also must remember it is reasonable to aim to "graduate" some patients from the most resource-intensive service input. In other words, a patient may need intense input at one point of their journey – perhaps while homeless before being securely housed, or while experiencing substance-related harm before being gaining access to harm reduction services.

In meeting the patient's needs, we hope to lead to a period of stability, where less resource expenditure will be needed. In some cases, the stability may even change the **trajectory** of their illness, by putting the patient in a better position (e.g. secure housing) so that they are no longer in a life-threatening situation. This reflects the purpose of palliative care: making a positive change in time for patients to see a benefit to their quality of life.

Conclusions

The recommendations in this report are not light touch; adopting them will require sufficient allocation and co-ordination of resources. It is natural to question how such recommendations can be practically applied in constrained systems with limited resources. Individual palliative care providers will need to work with colleagues in their local context to determine what is most appropriate in each local context.

Overall, I believe that by planning strategically to utilise and repurpose existing resources, we can effect inclusive approaches to palliative care. Putting resources into inclusive approaches for marginalised patients can lead to good returns on this investment. We can have more streamlined, efficient resource use, avoiding the expense associated with unplanned for emergencies and crises – all while providing patients a higher quality experience of care.

Recommendation Seven: Cultivate a place of peace

Providing a peaceful physical environment can give people time and space to rest from the difficulties and worries of life. Although power imbalances often exist between people experiencing marginalisation and people who are privileged, a place of peace should have reduced power disparities between patient and professional. Whether or not we are able to offer a discrete physical place of peace, we should strive in our work to create an environment and atmosphere or peace where patients, their loved ones, and workers can feel safe.

A place of peace

In this report, I focus on **trauma-informed approaches** for people experiencing marginalisation, including building safe relationships over time, and letting our patients know that we are safe people.

For example, in Recommendation One I explain the need to meet people where they are, make early contact, and be persistent in showing up for our patients. In Recommendation Four I explain the need for a harm reduction approach to substance use, which does not facilitate criminalisation of our patients. It is also important for us as caregivers to be safe and have space to express the feelings which come up in our work. I address this in Recommendation Nine, where I explain the need for those working with people experiencing marginalisation to be able to express and share their grief when a patient dies. We cannot provide a therapeutic environment free of traumatisation and **retraumatisation**, if we, as carers, become traumatised and develop compassion fatigue.

Therefore, to best support our patients I recommend the development of physical environments dedicated to fostering peace, safety, and healing for people experiencing marginalisation and those who care for them – including ourselves. The space should be designed for the needs of the people who it will serve. In my fellowship research, I found such environments in the form of bespoke gardens (see Box Fifteen, Page 81, and Box Eighteen, Page 88), but any other ideas for suitable spaces should also be considered. The spaces should be designed with the needs of patients in mind, ideally in collaboration with them. Accessibility (e.g. wheelchair access, hospital beds) must be considered in the design.

Discrete physical settings dedicated to peace may be experienced as a place of normalisation, i.e. they can allow, for a moment, people to feel some freedom from their pressures outside of the place. They can create environments of rest from marginalisation and traumatisation, where people can be themselves without fear of danger.

For example, a place of peace can give moments where a person who is in prison can be in a peaceful place and be removed from the stresses and expectations of prison. Likewise, a different environment could benefit a homeless person without a secure or peaceful place to live, to rest a while in the place of peace from the chaos they may experience elsewhere. The spaces should be free of judgement of the people who use them.

This sense of peace and normalisation can be enhanced by shared use of these spaces by the people experiencing marginalisation they are designed for and the people who care for them. This allows caregivers to have a much-needed space for rest and safety also.

For people experiencing marginalisation, power disparities with authority figures can be reminiscent of past trauma or otherwise difficult to deal with. The sharing of space between patients and their caregivers and other staff can create an environment where power disparities are reduced, and there is relaxation of roles. This can help us to see each other as people and increase empathy for each other, reducing any sense of '*us versus them*'.

The value of a place of peace in palliative care for people experiencing marginalisation is demonstrated by the prison hospice garden at **California Medical Facility** (See Box Seventeen, below). Here, the hospice garden was built by people in the prison for their use and according to their needs. The garden provides an environment which is greatly different from anywhere else in the prison, and it can be enjoyed by incarcerated people who are patients in the hospice, their friends and families, caregivers, and hospice and prison staff.

In my visit there, I learned other places in the prison often made people feel they constantly had to be on guard and conscious of the power dynamic between incarcerated people and prison correctional officers. In contrast, the garden provides a physical space where incarcerated people do not have to be on alert. They can enjoy the environment and the company of other people in peace.

For patients at the hospice, it is hugely therapeutic to experience this. Some of the patients are people who may have been in prison for much of their life. It is a healing experience, and a valuable part of palliative care, to be able to give them a place of peace to experience before they die.

Box Seventeen. The Garden in California Medical Facility, Hospice

The California Medical Facility Hospice (Box Seven, Page 66) has a communal garden within the hospice grounds. The garden was cultivated by a crew of incarcerated individuals, and includes a shaded patio, ornamental grasses, herbs, a water fountain, and gazebo. The garden offers a peaceful space which can be used by patients, carers, members of staff, and families of patients. Patients who are frail or unable to get out of bed can be mobilised into the garden in hospital beds to enjoy the space. It is experienced as a place of peace and normalisation within the walls of the prison.

Purposeful peace

Ideally, we should provide access to a physical environment of peace for people experiencing marginalisation, as above. However, we may not (yet) be able to provide a physical space of safety for our patients – but we ***can*** provide space for safety for people experiencing marginalisation by purposefully incorporating peace into everything we do. Such purposeful peace can be manifest in many ways:

- creating peaceful space in our conversations with patients – the space where we meet our patients (a private room if possible) should be an environment of peace and safety, even if only for the duration of our meetings
- being reliable – turning up on time and doing what we say we are going to do

- being consistent and not abandoning patients
- meeting people where they are (see Recommendation One)
- showing that we care for people regardless of their substance use and that we will not be contributing to criminalisation of their substance use
- acknowledging each individual is the expert in their own illness, their own life, and their own needs
- acknowledging when we are privileged and when we do not have the same lived or intergenerational experiences of trauma as the individuals we are caring for – and that we are open to being guided by them to alter our approaches and be as inclusive as we can be

Casey House is a subacute hospital in Toronto, Canada, caring for people living with HIV and at risk of HIV (see Box Eighteen, Page 88). Casey House was founded to provide care for people dying from AIDS in the 1980s. In response to the marginalisation that was typical at that time for people affected by HIV and AIDS, Casey House deliberately cultivated an environment of peace, acceptance, and positivity.

Today Casey House continues to provide care for people who are marginalised including people who are homeless, have been incarcerated, and people from indigenous groups. Casey House has a physical space purposefully designed for peaceful rest for use by patients, their loved ones, and staff, in the form of a rooftop terrace.

However, I observed that Casey House also goes further and exemplifies that the ethos of peace can be manifest in all aspects of patient care, ranging from medical and nursing, to supervised substance consumption, to music therapy and massage therapy. Although Casey House is a hospital, I observed that it contrasted with other medical settings in these ways, meaning it was not overly medicalised in its approach. Its entire organisation provided a space and an approach for patients to feel safe.

Conclusions

This report advocates for **trauma-informed** approaches for people experiencing marginalisation. We cannot always remove the problems and sources of trauma that our patients face in their lives, but we should strive to provide a therapeutic environment of peace where people can feel safe and they can rest from the stresses of life, if only for a while.

Ideally, we should provide a bespoke physical space of peace that is suitable for the needs of our patients. People experiencing marginalisation should have a leading role in designing and even building such a space to meet their needs. This is also beneficial to us as people working in palliative care: avoiding trauma to caregivers is important, and places of peace should also be of use by caregivers and other staff.

Furthermore, through patients, their loved ones, and caregivers making use of the place of peace together, hierarchies and roles can be relaxed or forgotten for a while, and mutual respect increased. Whether or not we are able to provide such a bespoke physical environment of peace, I hope that in all our endeavours for people experiencing marginalisation we can cultivate peace for our patients. We should purposefully incorporate peace into all our actions and communications with patients, including when enacting the recommendations made in this report.

Box Eighteen. Casey House, Toronto, Ontario, Canada

Casey House is a specialty subacute hospital in Toronto, caring for people who live with HIV. It also provides care for people at risk of HIV due to **social determinants of health**, such as people who are Indigenous; people who use drugs; people who have been incarcerated; men who have sex with men and gay, bisexual, and trans people who have sex with men.

Casey House was founded by journalist and activist June Callwood, to offer dignity and compassion in response to the crisis of many young men dying lonely deaths, while experiencing stigma and ostracism. Casey House was established in the 1980s, originally serving as the first dedicated hospice providing end-of-life care for patients with AIDS in Canada.

More recently, due to advances in treatments Casey House has expanded beyond having a focus solely on end-of-life care – now providing comprehensive inpatient and outpatient medical care for patients who live with HIV as a chronic disease, as well as end-of-life care for those who need it. The 14-bed inpatient unit provides 24-hour sub-acute care for reasons including infection, HIV comorbidities, and end-of-life care. Patients have access to supervised consumption services and various forms of therapy.

The ethos of Casey House includes a "conscious effort to bring joy to the space and to each other" – a positive environment contributed to by healthcare staff, therapists, and patients alike. This includes a rooftop terrace which patients, staff, and carers can make use of, and which they experience as a place of peace.

Recommendation Eight: Accept dying is different for every person

It is often difficult to recognise when a person experiencing marginalisation needs palliative care or when they may be dying. It is the people who know them best who will be able to detect subtle changes which may suggest decline in their condition. We must be open-minded to the need for palliative when concerns are raised, and these concerns may come from any source. We should also be cautious of having fixed expectations about the latter part of a patient's life and their death. How people may behave during their dying process is as diverse and variable as people's lives and their behaviour may not always fit with the conventional ideas of dying held in mainstream palliative care.

The right time to think about dying

Palliative care can make the biggest difference when it is commenced early for people with a life-threatening condition, but it can be difficult to recognise when any person may be approaching the end of their life or have a condition which is life-threatening. **Specialist palliative care** was designed originally to meet the needs of patients dying from metastatic cancer, which may follow a more predictable **trajectory** or pattern of decline and therefore be easier to recognise (see Page 27).

However, palliative care is for all with life-threatening conditions, not just cancer. Yet it may be difficult to know when palliative care is needed or to know if a person is dying or not. These challenges exist generally, but recognising dying is even more difficult in the case of people experiencing marginalisation.

There is no "one-size-fits-all" approach to dying, and no two dying people will be the same, even if they have the same underlying condition. There have been some efforts to help healthcare professionals to recognise when palliative care is appropriate. [90,91] One often cited way of detecting a patient who may need palliative care is to ask the **Surprise Question**:.[92]

The Surprise Question:

"Would be surprised if the patients were to die within the next 6–12 months[93]

For people experiencing marginalisation, the **Surprise Question** may be unhelpful. As described on Page 25, the risk of dying for a person who is homeless is high. Therefore, to ask the surprise question – '**would you be surprised if this person was to die in the next 6 months**?' or **'12 months**?' – may be very sensitive, as sadly the risk of dying is not surprising. However, it is possibly too sensitive to be of much practical use as the answer in nearly every case would unfortunately be the same.

A person experiencing marginalisation may not have an established relationship with a specified healthcare worker. The people who will therefore be best placed to recognise when palliative care is needed may be the patient her/himself and others who know them the best. This may include the person's friends, family or **chosen family**, and those working with people experiencing marginalisation, e.g. in the shelter system, in prison, or in harm reduction.

In Recommendation One, I emphasised the importance of inclusive palliative care having a low barrier to access. It is important that this includes a low threshold to acting on the concerns of people who know the person in question well.

Everyone, across sectors, should be observant for signs that the people they support may need more care. Signs of deteriorating condition to look out for can include:[2,34]

- general physical decline
- no longer moving around as well or as quickly as they used to
- apparent or confirmed weight loss
- withdrawing, becoming isolated, or not visiting with friends as much or doing the things they used to enjoy
- experiencing pain, shortness of breath, or other symptoms affecting their daily living
- being more muddled in thinking or memory changes
- more frequent hospitalisations or attendances at the emergency department
- longer stays in hospital
- depending on others in activities of daily living
- poor self-care
- changes in substance use like binge drinking (or unexpected request for detoxification)

These are only some of the possible changes that might signal that a person's condition is deteriorating. Those who see the affected person on a regular basis and know them well may spot other changes. **Healthcare professionals working in palliative care must be open to referrals for patients experiencing marginalisation from all sources**.

We must be conscious that the reasons for the concerns raised about a patient's condition might seem vague, but there is no exact science to identifying a person with palliative care needs. We must be open to providing care for people in need without being restricted by exact referral criteria or the need for specific signs or test results. We must also be alert that a person experiencing marginalisation may be dying even if they are of a relatively young age.

The good death

Palliative care was born out of the hospice movement of the 20th century (see Page 21). This movement brought with it modern ideas about what it means to have a **good death**. The typical view of the good death is an ideal often sought for our patients in contemporary palliative care. Our ideas of the good death might include:[17]

- the dying person accepting that they are dying and being a peace with this
- the dying person not receiving (or ceasing to receive) any invasive medical interventions
- the dying person having had the opportunity to reflect on their life and discuss their wishes and feelings in depth
- tight control of bodily functions and expressions of emotion
- being at peace with family present during dying and at the time of death
- being in bed in a comfortable environment like a hospice, with family present
- having financial affairs in order
- having resolved or overcome the difficulties faced during life by the time of death

Certainly, many people will share these ideas of a good death, and these will be things they would want palliative and end-of-life care to help them achieve. Of course, this will include some people from marginalised groups.

However, a person who experiences marginalisation may have different wants or behaviours as they are approaching the end of their life. We should be aware that often our patients' dying period is not going to fit with the above ideals of a good death, for example:

- a patient may be estranged from their biological family and may not wish to have any contact with them, may be frightened or inhibited to contact them, or may have conflicted feelings about whether contact is wanted or not
- the important people and loved ones of a patient may not be their biological family, but their **chosen family**: a group of people who are not blood relatives but provide them with social and emotional support
- a patient may not wish to engage in any discussions about their condition, their prognosis, or any type of anticipatory planning – possibly due to concentrating on their **survival imperative**
- a patient may not wish to engage in any kind of healthcare discussions or follow-up, or to be admitted to an institution, because of previous **traumatic experiences**
- a patient may not wish to stop using drugs or stop drinking alcohol before the point of dying

- a patient may not be able to leave or may not wish to leave a physical setting which healthcare workers may find far from ideal, e.g. a prison, a shelter, overcrowded accommodation.
- a patient may prioritise other factors over receiving healthcare including end-of-life care, e.g. avoiding admission to hospital so they can continue to be with their companion animal

In palliative care we are concerned with enhancing quality of life for our patients, but it is up to our patients to tell us what that means to them individually. We should not be paternalistic by imposing our ideas of the good death onto a patient who does not share those ideas. Inclusive palliative care approaches should involve us accompanying the patient in their life in whatever form that takes.

Ultimately, we should be guided by what matters to the patient in question. In our inclusive approaches we are ideally able to build up a trusting relationship with a person experiencing marginalisation over time through early contact and persistency (Recommendation One) therefore I hope we can find out the answer to the question of "what matters to you"? We must be willing to accept the answer when the concerns and wants for a person experiencing marginalisation may not be the same as we are used to from patients who are more privileged or who do not have **structural vulnerabilities**.

The important concerns for a person experiencing marginalisation with a life-threatening illness or who is approaching the end of their life will vary, but some examples might include:[34]

- what will happen to my belongings?
- who is going to look after my companion animal?
- who is going to remember me when I'm gone?
- who is going to be involved in memorialisation?
- will there be contact made with my estranged biological family members? (This may be wanted or not wanted)
- will my cultural traditions be honoured?

Hopefully when taken into someone's trust, we can be made aware of the important people they want to be contacted when they are dying or after they die.

During my Fellowship, I was aware of cases of people experiencing homelessness who were approaching the end of their life who continued, right until the point of death, to have lifestyles which were different from patients without **structural vulnerabilities.** From the perspective of mainstream palliative care, this might feel unsatisfactory: it may feel like we had never managed to calm the chaos in their lives. It may feel unsatisfactory because we never engaged the dying person in conversations about their mortality and did not hear that they had come to terms with their dying and felt at peace.

However, inclusive approaches to palliative care must mean respecting and being adaptive to different people's wants, behaviours, and lifestyles. Some people will want to engage in the conventional palliative care model of the **good death** described above, but for others this will not be wanted, or they may want to continue to live the way they have been living right up until the point of death.

Conclusions

Inclusive palliative care approaches must be cognisant of the fact that dying is different for every person. The signs that a person experiencing marginalisation needs palliative care may not be easily identifiable. We should take seriously when concerns are raised about people experiencing marginalisation, even though these concerns may be vague, without a fixed diagnosis or objective signs like test results, including when the concerns come from outside the healthcare sector from someone who knows the person well.

We should not have fixed expectations about what the good death might mean for our patients but should be conscious their wants and behaviours do not always fit with the conventional ideas of dying from mainstream palliative care. Ultimately, we should be guided by our patients' answer to the question: "What matters to you?"

Box Nineteen. Paul's Place, New York City, New York, USA

Paul's Place is a facility for people experiencing homelessness, operated by Center for Urban Community Services. It provides a low-barrier drop-in centre for 70-90 individuals (who can utilise recliner chairs) and also safe haven beds for 24 people with the most complex problems including chronic homelessness, mental illness, and recent incarceration or hospitalisation. There is access to lockers to securely store belongings, safe sharp disposal units, showers, laundry facilities, and meals provided. Paul's Place also provides healthcare consulting including a physician and a psychiatrist, and case management, supporting individuals to be placed in more secure housing. Paul's Place's approach aims to assist individuals experiencing street homelessness who have previously not engaged with other outreach services.

Recommendation Nine: Acknowledge and share grief

"Me? I'd just like to be remembered by somebody"[94]

Grief

Grief is an emotion experienced after the death or loss of another. Mainstream medical opinion often puts forward the idea that "normal" grief is short-lived, and that when grief is long lasting it is abnormal. This is reflected in the typical models of care available for people experiencing grief, like bereavement services which tend be time-limited and offer only a finite number of support sessions to individuals. After this period, it is expected that people will have recovered or moved on from grief.

Long lasting or complicated grief might even be classified by doctors as a medical disorder. For example, people experiencing sleeplessness, crying, inability to concentrate, and low appetite because of a loss could be given a diagnosis of depression, and those grieving for what the medical establishment deems to be "too long" may be diagnosed with prolonged grief disorder.[94]

Certainly, mental health care has a role to play in some cases. However, grief looks different for different people. Grief is a normal and reasonable reaction and can take a different length of time for each of us. We cannot clearly set parameters on what is "normal grieving" and what is not. Despite our medical models of grief, there is evidence that people frequently experience long-lasting grief that goes beyond what the medical community recognises.[17]

Furthermore, unrecognised loss or losses which do not fall within a framework of support can have lasting detrimental effects on health including predisposing to depression, heart disease, substance use, and premature death.[34] People experiencing grief which is not seen as valid by others in society can be said to be experiencing **disenfranchised grief** (Box Twenty, below).[95]

Box Twenty. Disenfranchised grief:

'The grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported'[96]

People experiencing marginalisation may be more likely to experience **disenfranchised grief** due to losses which may not be seen as valid by wider society including available bereavement support services. Such losses which might lead to **disenfranchised grief** might include:

- death of a **chosen family** member
- death of a fellow member of the street community
- death of a fellow person in prison
- death of a person due to suicide or murder
- death of a person due to HIV/AIDS
- death of a person due to drug poisoning or overdose
- death of a companion animal
- death of someone who has acted violently against the person grieving
- death of someone who has been the victim of violence by the person grieving

We should remember that people experiencing marginalisation may suffer multiple losses during their lives. For example, for a person experiencing street homelessness may have lost many members of their community over time. The death of people experiencing homelessness are more likely to be sudden and traumatic than the deaths of people who are stably housed, which can lead to more intense grief.[96]

For a person who is in prison, grief after losing a loved one may be complicated by:[97]

- isolation from sources of social support and inability to fully participate in death rituals (e.g. visiting the grave)
- limited choice around engagement with meaningful activities that might be helpfully distracting

- lack of freedom to use preferred coping mechanisms, e.g., spending time with people of their choice, going for a walk, cigarettes
- feeling lonely and alone
- institutional features e.g. over-crowding, confinement in a small space

For a variety of reasons, people experiencing marginalisation may not have been able to process their grief, have their grief acknowledged and seen as valid, or to talk to somebody about what they are feeling. This can lead to or exacerbate coping behaviours such as drug and alcohol use.[97]

Trauma-informed bereavement support

"Historically and presently, colonisation, racism, criminalisation, and discrimination fuel early deaths. There is constant death because of the drug poisoning crisis that disproportionately impacts poor and racialised drug users. Witnessing these unjust, unexpected, and unplanned deaths compounds the distress and pain of losing someone. The people you're supporting may have been denied access to prevention and treatment. Each death compounds the last because the injustice remains"[34]

For people experiencing marginalisation, the loss of a loved one can be traumatic and connected to other sources of **trauma**. So, considering how we respond to grief better is part of the vital work of making palliative care more **equitable**. We must remember the risks of death for marginalised communities are disproportionately high as a result of **structural vulnerabilities**. A **trauma-informed approach** therefore acknowledges that grief and loss are not separate from the issues of poverty, homelessness, criminalisation, or racism.

In the UK, **specialist palliative care** services are often connected to or can signpost people to grief counsellors. We must consider that people experiencing marginalisation who do not access medical care, for the reasons discussed in this report, are also unlikely to access or attend bereavement care and counselling through traditional routes.

Currently, in order to access most bereavement services, a person is required to agree to attend a number of sessions, refrain from drugs or alcohol during the sessions, and be open to talking about their loss. Ultimately the person accessing services must be able to trust the people working at the service. These requirements may be difficult to meet for people from marginalised communities, including those probably most in need of accessing bereavement support.[97]

There are already bereavement services demonstrating good practice by tailoring support to the needs of people who are homeless. Making bereavement support inclusive and accessible involves adopting **trauma-informed approaches** including:[98]

- ensuring services are available in the spaces where communities feel safe, rather than relying on individuals to come to institutions
- operating a flexible attendance policy to allow clients to test out services
- making the support a resource that can be accessed by choice rather than something that is imposed
- not revoking access to services for individuals who miss sessions
- being receptive to the different needs of individuals, which may differ from those not part of the same marginalised community

Inclusive bereavement care should also be aware of **disenfranchised grief** and be willing to support people whose bereavement is not seen as valid by mainstream society. I hope that inclusive bereavement services will be motivated by social justice, with a critical awareness of the structural issues which underpin trauma, grief, and multiple losses for people experiencing marginalisation.

Sharing in grief

Acknowledging a person's death is valuing their life

In healthcare organisations, including palliative care organisations, the usual workplace response to the death of a patient is one of carrying on as "business as usual". There are many tasks competing for attention, and workers tend to move on to quickly busy themselves with other activities rather than taking time and space to acknowledge that someone has died.

Expressions of grief by people working in healthcare are often seen as unprofessional. For example, in my experience, if a doctor was seen to be distressed by the death of a patient under their care, other doctors may question whether she/he has become overly attached to their patient and consider this to be poor boundary setting.

In my opinion, the prevailing culture of suppressing grief does not mean grief is absent among people working in healthcare, but that it is poorly acknowledged and handled. I believe that, since we should be motivated by our caring for our patients, it is natural and human to experience grief when the people we care for die. It seems to me a culture which shows disdain to open indications that we care for our patients is not a culture which values or facilitates us caring for our patients. This culture seems more likely to lead to worsened grief, burnout, and people eventually caring less for their patients, risking worse care provision.

For those working with people experiencing marginalisation, grief is complicated by the distress of observing unjust and inequitable deaths. People **structurally vulnerable** often die because of inadequate or failed systems. This is reflected in the far reduced life expectancy of people experiencing homelessness or imprisonment compared to the general population. Much of the distress experienced by people working in this space is not because of the work itself, but because of moral distress.

Those working with people experiencing marginalisation are at risk of **vicarious trauma**.[5] Workers are often over-stretching themselves to provide care in the face of absent care elsewhere. The limited amount we can offer to people falling between the cracks of society can be traumatising. Unjust loss of patients and lack of recognition of grief is itself traumatising.

Also, people experiencing marginalisation are often made to feel that their lives do not matter. For a person experiencing homelessness or in prison and approaching the end of their life, they may just want their life to have been important to someone. By carrying on with "business as usual" after they die, we are not acting in accordance with their wishes; we are contributing to the message that their life was unimportant.

A better approach to palliative care, then, is one of acknowledging and sharing in grief. In our inclusive approaches we should be motivated to value the lives of people experiencing marginalisation. Our **trauma-informed** approaches are also about reducing risk of traumatisation to staff. People working with marginalised communities must have a forum to express the distress they feel at the injustice faced by the people they have cared for and to have this distress validated.

Some ways in which teams and organisations can create opportunities to reduce **vicarious trauma** and to share grief include:

- openly preparing for the anticipated death of someone under our care (as grief is more traumatic when the death is not prepared for)
- offering formal support like counselling (which, as explained above, should **be trauma-informed** and critically conscious of the issues of **structural vulnerability**)
- not trying to "fix pain" or view grief as a disorder
- not telling people they should have gotten over grief by now
- collective debriefing
- opportunities for public remembrance and mourning (as below)

Public remembrance and mourning

> **"He had value to someone in his life [..] his life had meaning to somebody, he would not be forgotten"[100]**

Public mourning offers an opportunity to respond to grief collectively. It is a way for those affected by loss to express and share their grief and to know that we are not alone. Public remembrance and mourning can include non-professional people who were close to the purpose who died, including members of the same marginalised community, and professionals who were caring and supporting them.

Public mourning is also a public, proud declaration that the lives of people experiencing marginalisation had value. Examples of public remembrance and mourning can include formally organised events like a memorial service, but they can also be spontaneous. They can include banners, art displays, gatherings, and involve digital memorials, like The Dying Homeless Project which aims to remember and honour people from the homeless community who have died and to campaign for change so that further deaths may be prevented.[99] Activist marches against unjust deaths (e.g. from the opioid poisoning crisis) can also form a part of this public remembrance and mourning. These are continuations of caring for people who have been neglected by mainstream society.

People experiencing marginalisation should be empowered to be involved in and lead in celebrating lives of the people lost within their community. The form the public mourning takes should be adapted in accordance with the nature and personality of the person who has died or types of celebrations and rituals that are fitting with the particular community.[97] As always, we should be guided by the people we serve rather than imposing our own ideas.

Conclusions

For people experiencing marginalisation, grief can be complicated by multiple (often traumatic) losses which are often not validated by the rest of society, resulting in **disenfranchised grief.** Inclusive bereavement services must be mindful of these issues, taking a **trauma-informed approach** to improve accessibility and build trust with people who need their support. People experiencing homelessness or who are in prison often feel their lives are not valued by others, and hope that, when they die, their lives mattered to someone.

For those of us caring for patients from these marginalised communities, we should remember the lives of the people we serve are valuable and it is natural to feel sadness and grief when our patients die. Our distress can be complicated by the injustices faced by the people we care for, resulting in **vicarious trauma**. **Trauma-informed** palliative care approaches should therefore acknowledge and share grief.

Public mourning and remembrance activities can take many forms and are a way for people from marginalised communities, the loved ones of people who have died, and professionals who care for people experiencing marginalisation to share grief, emphasise the value of the lives lost, and know that we are not alone.

Recommendation Ten: Unlearning and change in the professional team and within organisations

People and organisations working in palliative care may not find it easy to implement these recommendations and to accept doing things differently. The way forward involves unlearning established norms and ways of thinking: changing the roles and expectations of staff, seeing people experiencing marginalisation as co-workers and colleagues, and changing our attitudes towards patients' use of alcohol and drugs.

"I don't ask my patients if they take drugs. They tell me if they feel comfortable, when they're ready"

- shared with me by a doctor working with patients experiencing marginalisation

The recommendations in this report are not easy to implement. It may not be easy for people working in palliative care to accept doing things differently. It will be difficult for organisations to adopt these changes. It may involve changing the roles and expectations of staff, the relationship between the organisation and the public, and perhaps even looking to new laws and regulations to underpin governance. Despite the challenges, we have a responsibility to strive for change.

For us to improve our approaches, I believe change not only necessitates learning new ways of doing things, but also involves **unlearning** conventional ways of doing things which are obsolete, obstructive, or harmful**.** While learning involves increasing one's capacities, skills or knowledge, **unlearning** involves the intentional giving up of previously established ideas or behaviours. Here,

I present some relatively simple examples of where the recommendations of this report run contrary to the status quo, and how I think we should challenge resistance to change.

Example: Patient communication

At present, we do not normally organise our work including our patient communication around the patient. In Recommendation One I explained the importance of early, pro-active patient contact, meeting patients where they are. Persistency is important in order to build up relationships with patients over time. For doctors, the vital importance of comprehensive assessment is drilled into us from medical school.

This includes thorough information gathering (the clinical 'history') from the patient. Typically, such assessment occurs in the first patient encounter when a patient is first consulted by a clinical service or admitted into a hospital or other facility. In other words, normal practice is to expect the patient to reveal their whole medical history and other personal details at first meeting.

In palliative care, a comprehensive assessment involves exploring the patient's wishes including their spiritual beliefs and where they wish to die – most people would, quite reasonably, consider these to be sensitive questions. However, when a patient is close to the end of life, we professionals may feel an urgency to gather this information as soon and quickly as possible, to allow us to provide an adequate care plan in time.

For a patient who has experienced **trauma** and who is distrustful of professionals, attempting to gather information about their life health, and symptoms may be invasive. Of course, gathering information is important, e.g. we cannot provide treatments unless we understand the symptoms the patient is experiencing and their underlying disease; we cannot help them connect with the people most important to them, if we do not know who these are.

However, in a **trauma-informed approach** we should accept that patients may not trust us and may not freely provide information immediately. We must show consistency to maintain contact with patients, and be willing to show that we can be safe people for them to confide in. This approach may include gathering information in a more piecemeal fashion, over several separate meetings with the patient as the relationship grows.

To effect this, we must accept this form of distributed patient assessment. At the same time, early contact is vitally important for patients with life-threatening illness: we must have the opportunity to build up the relationship in time to make a positive difference to the patient's quality of life.

Example: Seeing patients as co-workers

The relationship between patients and healthcare professionals is traditionally hierarchical. Despite guidance emphasising partnership between patients and clinicians,[100] typically there is a barrier between the healthcare worker (perceived as knowledgeable and powerful) and the patient (who is expected to do as they are advised).

Contrary to this, Recommendation Two focuses on peer-to-peer care and support, which involves recognising some patients, clients, and other non-healthcare professionals as care providers. Organisations such as the **California Medical Facility Hospice** (Box Five, page 63) and **PEACH**, Toronto (Box Three, page 60) provide examples of effectively involving people experiencing

marginalisation as colleagues to improve care of other people experiencing marginalisation. Recruiting people to work with their peers involves breaking down of barriers which previously existed: not seeing such a dichotomy between us and them.

Although it may be an uncomfortable change at first, it is necessary for healthcare teams to see patients, clients, and service users as equals in providing patient care. As has been demonstrated by **Amend** and **The California Model** in Californian prisons (see Box Twenty-One, below), such transformation of culture can be better for everyone, including improving the welfare and satisfaction of staff.

Box Twenty-One. The California Model and Amend, California, USA

The California Model is a transformational approach to the ethos across the California Department of Corrections and Rehabilitation. The model is based on learning from good practice in prison culture around the world. It is aimed at improving the welfare of incarcerated people and staff, and to facilitate incarcerated people adjusting to the community upon release and reducing risk of re-incarceration.

The California Model has four pillars:[103]

- **Dynamic security** – positive relationships built on positive, respectful communication between staff and incarcerated residents
- **Normalisation** – making life in prison as close as possible to life outside prison
- **Peer mentorship** – incarcerated people mentor and support their peers
- **Becoming a trauma-informed organisation** – changing practices, policy, and culture at all levels.

Amend, a public health and human rights programme from University of California San Francisco, works with prisons for changes to reduce negative health effects on residents and staff.[104] I had the opportunity to observe training delivered by Amend to health and correctional staff in a Californian prison about adopting the California Model. I observed that it is possible facilitate cultural change within an established organisation, and help stakeholders shape new ways of practising.

Example: Attitudes to patients' self-medicating and substance use

In my experience of medical training and practice in United Kingdom, the general approach to patients living with alcohol dependency and people who use drugs (**PWUD**) has been a promotion of abstinence. A hospital team may, for example, cease providing care if they discover a patient using non-prescribed substances on the premises and eject the patient from hospital.

In my experience of UK palliative care, there is generally an expectation of patients being abstinent from non-prescribed drugs. This is acceptable to some patients: some may wish to be supported to undergo medically supervised withdrawal leading to total abstinence from non-prescribed drugs. However, many others will not wish this and may not wish to be admitted to a place of care due to concerns about substance withdrawal.

Also, patients may fear that their pain will be undertreated by healthcare professionals because of a background higher tolerance to certain types of drugs or because they may be perceived as malingering or "drug seeking". Clearly, such factors can be alienating for people with alcohol dependency and **PWUD.**

Recommendation Four focuses on integration of harm reduction principles into palliative care. This is based on the principle of accepting that some patients use substances, but working in a non-judgemental, non-coercive way to reduce the harms associated with substance use. Such harm reduction may include provision of alcohol to patients living with alcohol dependency (Managed Alcohol Programmes) or, depending on legal restrictions, potentially supervised consumption of drugs which have been obtained elsewhere.

Such approaches are not currently found in UK palliative care settings, and their introduction would require significant organisational planning, and a readjustment for healthcare staff. There may even need to be legal changes or a case made for legal recognition of safer consumptions sites. However, if we wish to engage with patients experiencing marginalisation because of substance use through inclusive approaches, meeting people where they are should involve expecting and, when possible, accommodating their substance use.

Example: Health care worker emotion

In healthcare we are discouraged from expressing emotion. As a medical doctor, I find people in my profession tend to emulate the conventions of the profession, including what is modelled for us by our colleagues. Part of the process of becoming and continuing as a doctor is to learn not to show emotions.

For example, when I worked in acute and general medicine, every day we were faced with patients who were critically unwell, and often had patients who died under our care. Yet there was no external acknowledgement of any of distress among doctors about the situation of the people we were caring for. We just moved on to the next patient, as if nothing significant had happened. Any expression of emotion was even criticised or ridiculed.

Now in palliative care, despite the ostensible recognition of the person as a whole being, I have been surprised to see a similar lack of space for expressing emotion among the healthcare team. We get to know patients and their loved ones, providing care at a very significant time in their life, and often spending time with them as they face the most difficult things they have ever had to face. And yet I have not experienced an environment where palliative care workers can openly express the emotional impact of their work. We carry on regardless.

In my opinion, the suppression of feelings of care for our patients and their loved ones does not cultivate a culture of care towards our patients and their loved ones. On the contrary, I believe the convention of professionals acting like they are unaffected by the pain of patients and their loved ones suggests more of a culture of lack of care towards patients and their loved ones. Furthermore, when professionals express compassion only for certain patients, but not for others (for example **PWUD**), it is not difficult to see this can lead to differences in level of care provided to different patients.

In Recommendation Two, I explain the importance of peer-to-peer care and, as I have expanded on above, this involves a breaking down of the barriers between patients or service users and healthcare teams. Inevitably this makes us more vulnerable.

In Recommendation Nine, I explain the importance of acknowledging and sharing grief. This is particularly important for people who have experienced marginalisation for reasons such as homelessness and drug use, who often have felt that their lives do not matter to anyone else. I would like to think, in adopting the inclusive approaches to palliative care I describe in this report, people working in palliative care will tell our patients implicitly and explicitly that their lives have value.

I believe this must be manifest also in how we as palliative carers express our feelings. It is not right to react with indifference to the suffering and death of a marginalised person and simply busy ourselves with the tasks of our working days. The changes I recommend in this report require us to be accepting of our emotions when we care deeply for our patients. We must develop a safe environment in which to acknowledge, give space and time to, and express our emotions in the most helpful way possible.

Conclusions

Above, I have discussed a few examples of the challenges the recommendations in this report place for individuals and teams working in palliative care and for palliative care organisations.

In order for us to move forward to give care to everyone who needs it, we cannot stay stagnant. We must change. I invite those working in palliative care to rise to these challenges: to unlearn whatever holds us back from providing the care patients deserve, and to learn new ways, collaboratively with one another and with patients, especially those who are experiencing marginalisation.

Summary

I started this report with the premise that palliative care has a problem. Yes, palliative care is a force for good in reducing the suffering of people who have access to it, but the problem lies in **inequity** of access. Currently, people who are marginalised have **inequitable** access to high-quality palliative care, despite having complex and often greater need for palliative care.

To address this problem, this report has presented ten recommendations for adopting inclusive palliative care approaches for people experiencing marginalisation in the UK, derived from my research at centres of care in the USA and Canada.

I have focused specifically on two **structurally vulnerable** groups who are currently under-served by UK palliative care: people who are in prison and people experiencing homelessness (encompassing all forms of homelessness and vulnerable housing). There is a large overlap between these groups and with other **structurally vulnerable** groups (especially with people who use drugs and with people living with **Severe and Persistent Mental Illness**), and so the recommendations are likely to be of value when considering inclusive approaches generally. For people who experience homelessness and for people in prison, there are several barriers to adequate palliative care provision (see Pages 25 and 32). The recommendations in this report were devised by applying my learning from my research to find ways to overcome the barriers described.

Awareness of **trauma** is also a crucial part of these recommendations. It is common for people who have been diagnosed with a life-limiting illness to have **trauma-associated** symptoms, and healthcare can itself be a source of **trauma**. This is even more of a concern for people experiencing marginalisation, as they have often experienced significant trauma in their lives, meaning that their experience of life-limiting illness and encounters with palliative care present even greater risk of traumatisation and **retraumatisation**. Due to self-preservation, people experiencing marginalisation may not respond well to or engage at all with established models of palliative care, in order to avoid **retraumatisation**. To reach **equitable** care which works for people experiencing marginalisation, we therefore must take **trauma-informed** approaches.

It was therefore vitally important to me that these recommendations promoted **trauma-informed** care. I have been mindful of the key principles for **trauma-informed approaches** in forming these ten recommendations: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; sensitivity to cultural, historical, and gender Issues. I ask everyone reading this report and considering the recommendations to remember that these **trauma-informed** principles should be integrated when following any of the recommendations and should be integrated into all our approaches. There is no one-size-fits-all to being **trauma-informed**. We all need to be guided by what our patients tell us they need. **Pain is what the patient says it is.**

I have been privileged to have learned from many inspiring and deeply caring people working with patients at the margins of society. I was privileged to observe care provided by individuals and to visit innovative organisations. Most of all, I was privileged to meet people experiencing marginalisation who shared valuable insights into their life with me and described the difference that inclusive approaches can make for them.

In conveying each of my recommendations, I have linked back to organisations and individuals who helped me in determining that recommendation. This work would not have been possible without the incredible generosity that has been shown to me in my research process, and I hope that I have done justice to those who contributed to this project.

"Our job is to love others without stopping to inquire whether or not they are worthy"

- Thomas Merton[105]

I have advocated for a broad understanding of palliative care. Yes, we should be motivated to take actions to try to remove our patients' problems, but even when it is not possible to eradicate these problems, we can still reduce suffering by accompanying people in their lives. For people experiencing homelessness and people who are in prison, especially those approaching the end of their lives, it may not be possible to remove sources of suffering and our patients may not wish their social circumstances to change.

The value of palliative care is in the **care**, and that includes ***being with*** our patients on their journey regardless of their circumstances (reflected in particular in Recommendations One and Eight).

We should also broaden our understanding of palliative care when considering who provides it and when it is provided. Palliative care exists whenever care and support is being given to enhance the quality of life of a person with a life-threatening condition or circumstance, provided by professional and non-professional carers, no matter the setting or discipline. This vitally includes people experiencing marginalisation themselves when they support their peers, therefore acting as palliative care providers (see Recommendation Two).

This report is for people working in palliative care, and people working in general healthcare – whose role will inevitably include palliative and end-of-life care at least some of the time – but also people working and volunteering across all disciplines, including social services, homeless sector, and the prison sector. Palliative care is provided by everyone working to enhance the quality of life of people experiencing homelessness and people in prison – not just healthcare workers. Given the vital importance of housing to health and to quality of life, we must acknowledge housing as part of the spectrum of palliative care. I hope in the future we will see the provision (or prescription of housing) as an integral and achievable part of inclusive palliative care (as per Recommendation Three).

I hope that this report can encourage better appreciation of the role of different sectors and better ways of working together. Presently, major barriers for marginalised patients include lack of recognition of the need for palliative care among people who are homeless and people in prison, lack of awareness of the availability of different services, and lack of efficient communication between professionals and services. In taking forward the recommendations of this report, I hope that we can overcome these barriers and work towards:

- greater recognition of the risk of dying among people experiencing marginalisation, including young people (see Recommendation Eight)

- better awareness between services of each other's role and scope, including awareness that everyone has the right to palliative care including referral to **specialist palliative care** services
- better working relationships between services, with clear, efficient lines of communication
- more streamlined and flexible use of resources to achieve the best possible outcomes for the patient (in line with Recommendation Six)
- cultural change within organisations to allow for reducing power disparities, acknowledgement and sharing of grief (see Recommendation Nine) and flexibility to move away from conventional ways of working (see Recommendation Ten)
- including people who are or have been affected by homelessness and people who are or have been in prison, as our co-designers in devising new models of care which work better for people experiencing marginalisation

"Hope is the thing with feathers

That perches in the soul

And sings the tune without the words

And never stops - at all"

- Emily Dickinson[106]

This report does not set out precisely how to achieve inclusive palliative and end-of-life care for marginalised patients. The recommendations are not prescriptive, and each individual and organisation using this report must consider which of the recommendations can be adopted and adapted to your context and to the people you care for. I understand the recommendations presented here may be challenging.

Making changes may be difficult and resource-intensive to introduce and may take a long time. At present it may be even impossible to adopt some of the recommendations before relevant changes in law or regulations, especially when it comes to more flexible substance policies and harm reduction approaches (see Recommendation Four).

Forging the path ahead to more inclusive approaches in palliative and end-of-life care will be challenging but also exciting. I believe that by working together, we can develop new and better ways of working and ultimately better outcomes for our patients.

We should remember that **palliative care is a revolutionary practice** which was born of a desire to break away from the old ways of doing things in order to help those in need. I hope that we can be inspired by this revolutionary spirit, and that his report can spark discussion, innovation, and changes to bring excellent palliative care to everyone who needs it.

The future: working together

I hope these recommendations will trigger conversations and reflection for you, your teams, and your organisation. It is my aspiration that the ideas generated from this work inspire innovation and development which leads to improved **palliative and end-of-life care at the deep end**.

It would be fantastic to open up lines of communication about new ways of working and to form a community of practice focused on providing palliative and end-of-life care for people experiencing marginalisation.

I hope the community of practice will include people with lived experience of marginalisation, whose voices should be absolutely central to developing new models of care to meet the needs of marginalised people.

I am learning all the time and keen to expand my knowledge and skills in this space, so it would be my privilege to learn from anyone who is able to share their experience and expertise with me.

Please feel free to get in touch to:

- discuss your thoughts on this report
- share your experience and ways of working
- discuss how you are thinking of taking on the recommendations made in this report – or whether you think they should be modified or changed
- seek more information or discuss me presenting this work to your team or at your event
- consider potential ways of collaborating
- forge and expand networks
- share ideas to work with our patients, service-users, and other people experiencing marginalisation to co-design new models of care which work for them

You can get in touch with me using the contact form on my website

Or email me directly at deepend.palliative@gmail.com

It is exciting to see the direction of future work in palliative care for people experiencing marginalisation. I greatly hope we can work as community towards better outcomes for people who are currently under-served. I look forward to hearing from you.

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Glossary

ACEs
Abbreviation, see **Adverse Childhood Experiences**

Adverse Childhood Experiences (or **ACEs**)
Traumatic experiences occurring in the life of a person before the age of 18 years old. These experiences strongly correlate with negative outcomes in later life, sometimes occurring decades later, including substance use, mental illness, and chronic physical illnesses.

Chosen family
A person or group of people who are not blood relatives but provide another person or each other with the social and emotional support of a family.

Disenfranchised grief
Grief that a person experiences when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or supported by mainstream society.

Equality
In the context of this report, **equality** is used to mean when every person has or is given access to the same care, regardless of whether it is right for them.

Equity
In the context of this report, **equity** is used to mean when every person has or is given access to the care that is right for them, adapted based on their individual needs.

Equitable
See **Equity**

Generalist palliative care
In the United Kingdom context, **generalist palliative care** is used to describe palliative care which can be provided by all healthcare professionals, in every healthcare setting, whenever a person needs it. This may be provided across the health service, by healthcare professionals including general practitioners, district nurses, nursing home staff, home care staff, hospital doctors and nurses, physiotherapists, occupational therapists, and social workers. The National Health Service in the UK can provide aspects of **generalist palliative care** without financial charge to the patient.

Housing First
The approach of offering permanent housing to homeless people as quickly as possible, bypassing transitory accommodation options, without pre-requisites, and combined with holistic, **trauma-informed** attitudes.

Inequity
When **equity** is not present. See **Equity**.

Illness trajectory
The effect of illness progression on a person's life, influenced by disease process, treatment provided, exacerbations, remissions, and the dying phase.

Multiple exclusion homelessness
The deep social exclusion of those affected by homelessness plus institutional care (e.g. prison), substance use, or involvement in street culture activities (e.g. begging and street drinking).

Post-Traumatic Stress Disorder (or **PTSD**)
A mental health disorder resulting from one or more traumatic experiences. Diagnosis requires a specific combination of features including intrusive symptoms, persistent avoidance of stimuli associated with the traumatic event, negative alterations in thinking or mood, marked alteration in arousal or activity, and significant impairment in functioning. Most people who have been traumatised do not go on to receive a diagnosis of **Post-Traumatic Stress Disorder** as they often experience some of these symptoms but do not reach the full diagnostic criteria.

PTSD
Abbreviation, see **Post-Traumatic Stress Disorder**

PWUD
Abbreviation for people who use drugs

Retraumatisation
Occurs to an already traumatised person when something in a present experience is reminiscent of a past **traumatic experience**. This causes the affected person to become traumatised again.

Severe and Persistent Mental Illness (or **SPMI**)
Mental illnesses that are prolonged and recurrent, impair activities of daily living, and require long-term treatment, including schizophrenia, bipolar disorder, and major depression.

Social determinants of health
Non-medical factors influencing health including conditions, like working and living conditions, and wider systems, like economic policies and social norms.

Specialist palliative care
In the United Kingdom context, **specialist palliative care** relates to care provided by professional individuals or teams branded with the defined role of palliative care. **Specialist palliative care** is often based from hospices but can be provided for people who are at home, in-patients in hospital, in-patients at a hospice unit, visitors at day units, residents of care homes, or people who move between these settings at different times of their life.

Examples of healthcare professionals who are involved in delivering specialist palliative care include: doctors who specialise in palliative medicine, clinical nurse specialists, specialist physiotherapists and occupational therapists, counsellors, chaplains, and nurses who work in a hospice. **Specialist palliative care** is also available free of charge to the patient in the UK, however in many cases it is provided by charitable organisations which are largely funded through charitable donations.

SPMI
Abbreviation, see **Severe and Persistent Mental Illness**

Structural vulnerabilities
See **structurally vulnerable**

Structurally vulnerable
When people are made vulnerable to worse outcomes in life because of power imbalances reflected in social, economic, political, and cultural systems. These power imbalances result in social hierarchies, with those at the bottom of the hierarchy being the most **structurally vulnerable**. Negative outcomes for **structurally vulnerable** people include: the least choices and opportunities in life, the least access to healthcare, the greatest risk of harm, the greatest risk of neglect and abuse, and the poorest health including chronic illnesses and premature death.

Survival imperative
The state of being so taken up with the immediacy of daily struggle for the basic necessities of survival (including safe shelter and meals) that other needs are overlooked, such as healthcare needs.

Trajectory
See **illness trajectory**

Trauma
The lasting psychological and biological condition which affects individuals following a **traumatic experience.** It is characterised by **trauma-associated symptoms.**

Trauma-associated symptoms
In the context of this report, used to describe symptoms commonly experienced by traumatised people. This represents that most people who have experienced significant trauma do not go on to obtain a full diagnosis of **Post-Traumatic Stress Disorder** but do experience **trauma-associated symptoms**.

Trauma-informed
When an individual, team, or organisation recognises the widespread impact of trauma on the people they serve and respond by integrating knowledge about trauma into policies, procedures, and practices, and seek to actively resist **re-traumatisation**.

Traumatic experiences
Experiences which threaten a person's physical, emotional, or social well-being. They are overwhelming experiences which cause feelings of fear, lack of control, and helplessness, and are beyond a person's sense of their capacity to cope.

Trauma-informed approaches
Approaches undertaken by **trauma-informed** individuals, teams, or organisations. See **trauma-informed**.

Tri-morbidity
The combined impact of physical illness, mental illness, and substance use on people experiencing homelessness.

Unlearning
Improvement by intentionally moving away from conventional ways of doing things which are obsolete, obstructive, or harmful, including giving up of previously established ideas or behaviours.

Vicarious trauma
The traumatic effect on people who work with traumatised people. **Vicarious trauma** is made more likely by witnessing the unjust outcomes and deaths of **structurally vulnerable** people.

Reference list

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