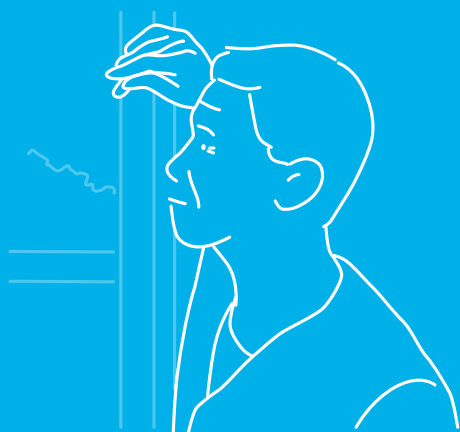


# ISSUE FOCUS

## Mental–Emotional Health and the Human Rights of Older Persons

ASEM Global Ageing Center





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**Mental–Emotional Health and the Human Rights of Older Persons**

ASEM Global Ageing Center

## ACKNOWLEDGEMENTS

We would like to express our gratitude to the AGAC Issue Focus Advisory Group – Jung-Hwa Ha at Seoul National University, Sabine Henning at the United Nations Economic and Social Commission for Asia and the Pacific, Mijin Lee at Konkuk University, Silvia Perel-Levin at the NGO Committee on Ageing in Geneva, and Margaret Young at the Global Alliance for the Rights of Older People. They provided general guidance on the outline and theme of this report.

Valuable insight and input were provided by the contributors to this issue – Eunsoo Choi at Korea University, Debanjan Banerjee at the APOLLO Multispecialty Hospitals, Kiran Rabheru at the University of Ottawa, Carlos Augusto de Mendonca Lima at the World Psychiatric Association, Gabriel Ivbijaro MBE at Waltham Forest Community & Family Health Services, Robin Hewings at the Campaign to End Loneliness, Carmen Valle-Trabadelo at the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergency Settings, Sarah Harrison at the IFRC Reference Centre for Psychosocial Support, and Laure Garancher at The Ink Link.

We hope that this edition will inspire international advocates for older people's human rights, and contribute to improving quality of life for older persons, particularly in the often-neglected areas of mental health and emotional well-being.



**Eun-Hee Chi**

Executive Director, ASEM Global Ageing Center (AGAC)

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**AGAC Issue Focus Advisory Group** is a group of experts focused on ageing and the human rights of older persons, and provides advice on the themes and topics of Issue Focus and feedback on the volumes. The advisers share their insights and views as well as their regional expertise around the world. Issue Focus addresses the issues and agendas of ageing that are relevant to all ASEM partners.

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# INTRODUCTION

**Eunsun Lee**

*ASEM Global Ageing Center*

The world is becoming increasingly uncertain, with life pressures driven by humanitarian emergencies around armed conflict and climate change, by health crises in the form of recurring pandemics, and by the ongoing Fourth Industrial Revolution, which is accelerating digitalization. Meanwhile, global demographics show a rapid increase in the proportion of older persons; by 2050, they are expected to account for 22 percent of the world’s population (World Health Organization, 2021).

Uncertainty, a feature of the current moment that is likely to metastasize to the future, is often conceptualized as intrinsically pathogenic, since much contemporary research has demonstrated that uncertainty is linked to a variety of worsening mental health problems, including depression, anxiety, psychological distress, post-traumatic symptoms, stress, emotional exhaustion, psychosomatic complaints, and hopelessness (Massazza et al., 2022). However, there is also counter-evidence to argue that uncertainty is associated with positive psychosocial variables such as hope (Gill & Morgan, 2011), prolonged positive moods (Wilson et al., 2005), and optimistic attitudes (Brashers, 2001).

## In tenebris

In the midst of this ambiguity, news from around the world mostly conveys stories that appear to support the pathogenic aspect of uncertainty. The conclusion must be that this is likely to jeopardize the healthy ageing of older persons – that is, the present and the future “us.”

To begin with, more than 20 percent of adults aged 60 and above suffer from mental or neurological illnesses, excluding headache disorders. Furthermore, healthcare professionals and older individuals frequently under-identify mental health conditions,

and the stigma that comes with these diseases makes it difficult for older persons to seek help (World Health Organization, 2017).

Even under prolonged conditions of stress, older adults are found to be similar to or superior to their younger counterparts in terms of social and emotional resilience (Carstensen et al., 2020). This is because, as their perspective on time shifts, older people become increasingly motivated to pursue their emotional well-being and their purposes in life, and they gain more knowledge about how to regulate their emotions as a result of life experiences. However, in the face of inescapable negative events that increase the risk of distress, these advantages may fade, or wane entirely, resulting in physical and mental health disruptions (Charles & Carstensen, 2010).

Considering these attributes of older persons and their mental and emotional health, a world filled with high degrees of uncertainty will arguably increase their vulnerability and further threaten their human rights. For example, despite the promising use of Information and Communications Technology (ICT) for older adults' well-being (Sims et al., 2017), the Fourth Industrial Revolution's rapid expansion of digitalization may leave older persons excluded and disempowered in society, partly due to their lack of digital skills and experience. As a result, they will have low self-esteem and self-efficacy and will be unable to fully exercise their rights (UNECE, 2021). In addition, despite the fact that the impact of long hours of social media usage has primarily been studied with younger adults to date, the same may also aggravate older adults' psychological issues, such as loneliness and depression. As much as younger people, they may be affected by cyber harassment and ostracism, an insufficient number of "likes" and clicks, and pervasive images of others' seemingly perfect lives (Nobel, 2018).

Public health hazards, such as COVID-19, are also likely to have compounded the mental health issues that some older people experience. Loneliness and social isolation may be as harmful to people's minds and bodies as smoking 15 cigarettes a day, and contribute to early mortality (Holt-Lunstad, 2017). The number of lonely people and the frequency with which they feel lonely appear to have increased since the pandemic began (Weissbourd et al., 2021).

Climate change may also have a profound impact on the mental health of older adults. For example, older persons have been reported to experience high degrees of post-traumatic symptoms, anxiety, and depression after floods (Leyva et al., 2017).

A cursory examination of humanitarian emergencies worldwide, such as the situations in Ukraine, Myanmar, Syria, and Cameroon, reveals that older persons will need the maximum amount of psychosocial support. After the 2014 dispute over Crimea, for instance, 96 percent of the older persons surveyed responded that they had suffered from war-related mental health issues, with some still recovering (HelpAge International,

2022). Furthermore, Ukraine is one of the most rapidly ageing countries in the world, leading to concerns about the consequences of the ongoing war on the mental health of older Ukrainians (AGE Platform Europe, 2022).

Older persons in armed conflict zones feel as if, in the face of the devastation of their life's work, property, and home, "someone [is] ripping your heart out and throwing it" (Mahdi, 2021, as cited in Human Rights Watch, 2022, p. 3). They describe how "[armed groups] took all that gives us meaning – our husbands [and wives], our children, our clan chief, our imam, our animals ... I begged them to kill me too" (an older woman, 2021, as cited, 2022, p. 19). They say, recounting an episode of torture and other ill treatment, "I was too scared. I just sat there shivering and crying" (Shahkeldyan, 2020, as cited, 2022, p. 25). However, there are only a few mental health and psychosocial support services available for older persons in these situations (Human Rights Watch, 2022): "no one thought of psychosocial care for older people. [The humanitarian response is] deprioritizing older people's mental and physical well-being" (the Bangladesh country director of an international humanitarian organization, 2019, as cited in Amnesty International, 2019, p. 32).

## Ex nihilo nihil fit

Since many older persons face a risky world full of uncertainties and a range of disadvantages, including mental and physical illnesses, and the stigma associated with them, we need to ask where we position our ideals regarding the human rights of older persons, and what we think, feel, and do about them. We may have been amnesiac about the axiom that "humanity, which is present in even the lowliest of people, gives each individual a dignity and status that must be respected by all other individuals, society, and the state," and that human rights are a concrete embodiment of that respect (Donnelly, 2013, pp. 128–129).

However, there are scholars and practitioners who try to set a better course against this flow of global forgetfulness in a world divorced from these ideals, and who may provide us with ways out. We present four reports from their endeavors.

Choi uses sociometer theory to explain the importance of an individual's sense of others' acceptance of themselves, since humans have evolved to value social inclusion, and socioemotional selectivity theory to explain older persons' particular tendencies to pursue high-quality social relationships. Drawing on empirical data, Choi demonstrates that positive social interaction is more critical in older age groups than in other age groups, and that it protects against mental disorders such as depression. Choi argues that, in the face of the loneliness epidemic, newly established relationships formed through social participation can serve as satisfying networks for older persons, and be beneficial;

we should therefore provide them with these opportunities.

Banerjee, Rabheru, de Mendonca Lima, and Ivbijaro lead us to the idea of dignified geriatric care, calling for the conceptual clarification and acceptance of dignity in mental healthcare for older persons. Banerjee and colleagues discuss stigma and discrimination against mentally challenged older adults, the psychosocial toll COVID-19 takes on them, the social determinants linked to mental disorders, dignified life in residential care, the issues of homeless, frail, and dementia-suffering older adults, their decision-making capacity, excessive medication, and end-of-life concerns, as well as innovative healthcare technology. Finally, the authors recommend ways to protect and promote the dignity of older persons, including a UN Convention for their rights as a legal framework.

Hewings introduces several scientifically-backed remedies to the loneliness epidemic that are currently being implemented in the UK, a leading country in this arena. Direct solutions, connector services, and gateway infrastructure are among these interventions. Hewings expects an increase in the severity of loneliness in the future and encourages individuals and organizations to join the Global Initiative on Loneliness and Connection, a rising movement to tackle loneliness.

Valle-Trabadelo, Harrison, and Garancher describe the process by which they developed “Living with the Times” for older adults’ mental health and well-being during COVID-19, a visual, poster-based project that is versatile in diverse situations, including locations, audience levels, and contexts (e.g., humanitarian and rural contexts). Their approach was democratic and deliberative: professionals and older persons from 51 countries provided input, informing stakeholders on how to execute similar projects.

We are confident that these four reports will help illuminate the uncharted waters surrounding the mental and emotional health of older persons and their human rights. As we navigate toward a world in which the gap between our aspirations and reality is filled, we promise to recruit many more insightful persons here to Issue Focus to spur our collective effort. *Semper ad meliora et ad majora.*

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# Being connected matters, especially for older adults

**Eunsoo Choi**  
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## Increasing numbers of older people living in Korea are suffering from social isolation

The proportion of older persons in the population is increasing worldwide, but the rate in South Korea is strikingly high. As of 2021, 16.5 percent of the population is 65 years and older, and this trend will continue. It is estimated that within just four years, this group will make up over 20 percent of the population (Statistics Korea, 2022), meaning Korea will join the ranks of super-aged societies alongside Japan, Italy, Finland and others.

One characteristic worth noting is that a significant proportion of the older population in Korea live by themselves. There are over 1.6 million older adults who live alone, meaning 35.1 percent of this age group (Statistics Korea, 2021). And of those who are above 70, nearly half (44 percent) live alone. Considering that across the world, the average percentage of older adults living alone is 16 percent (Ausubel, 2020), the Korean figures are compelling. Even more startling is the fact that the number of older persons living alone keeps increasing. Statistics Korea estimates that this number will double by 2037 when over 3.3 million older people are likely to be living on their own in South Korea (Statistics Korea, 2020).

Solo households seem quite familiar now, but until recently, living with an extended circle of relatives was the most common type of household arrangement in South Korea. However, as the economy grew, South Korea went through a radical social transformation that impacted every aspect of society, including family arrangements. Parents in the countryside began living apart from their children as the children went to the cities for better education and jobs, never to return home. The nuclear family replaced the traditional extended family, and older adults began to live by themselves. Adding to this,



divorce among older people has been growing fast in recent years, resulting in an even greater number of solo households among older people (Jung, 2022). Overall, the changes in social structure, as well as in the values and norms that are intertwined with the social system, have contributed to the growing trend of older adults living alone. And because South Korea went through societal change in such a short period of time, both individuals and social institutions have been struggling to find ways to adjust to the new way of living.

As the number of older people living alone increases, social isolation and accompanying feelings of loneliness are becoming an epidemic that has real consequences. A recent analysis revealed that the major cause of depression among older adults was indeed loneliness (Lee et al., 2021). With this in mind, the present article will discuss how loneliness can be detrimental to people's well-being, especially in later life. Recent empirical findings of older adults in Korea will be introduced to make the case that being connected with others is an important source of mental health, particularly in later life. Finally, potential solutions for dealing with older people's loneliness are suggested through a review of the relevant literature.

## **Loneliness and social isolation are harmful**

Although social isolation is not necessarily linked to negative outcomes, since one can be socially active while being relatively isolated, it becomes increasingly difficult for older people, especially if they are living alone, to be socially connected, as they have withdrawn from work and have fewer opportunities to interact with others.

Social isolation, which is marked by having few social contacts and social network ties, has significant costs. Considerable research has documented a host of dire consequences, for both physical and mental health. Being lonely predisposes a person to a higher stress response, inflammation, and a weakened immune system, which are all risk factors for premature death. One recent meta-analytic review that analyzed over 3.4 million people from 70 studies revealed that the mortality risk is 30 percent higher for those who are socially isolated (Holt-Lunstad et al., 2015). In fact, the detrimental effects of social isolation are not limited to older adults; children are also at risk (Caspi et al., 2006).

The key psychological condition that socially isolated individuals suffer from is loneliness, a distressing emotional and cognitive experience of dissatisfaction due to the discrepancy between one's desired and actual social relationships (Perlman & Peplau, 1984). The subjective experience of loneliness is known to be associated with emotional problems such as depression and anxiety (Cacioppo et al., 2006) and cognitive decline in older adults (Donovan et al., 2015).

It is not surprising that loneliness predicts mood problems like depression and anxiety, given the central role that social relationships play in human functioning. Social scientists have long assumed that human sociality is central to individuals' survival. For instance, sociometer theory by Mark Leary and Roy Baumeister (2000) suggests that because social inclusion has been crucial for survival in human evolution, we have developed an internal system that signals whether or not we are accepted by others. That is, one's sense of self-worth (i.e., self-esteem) is determined by how much one thinks that he or she is liked by others. From this point of view, it is no wonder that lonely people are prone to experience the negative emotional state of feeling worthless, one of the key symptoms of depression.

## **Social relatedness is an antidote to loneliness for older adults**

The natural countermeasure to loneliness is, then, connection with others; more crucially, a subjective sense that one is cared for and supported by people who are significant in one's relationships. One might think this perception of social support would be more relevant, more important for one's well-being, for younger adults, who are active participants in all realms of social life. It is true that the number and size of people's social networks become smaller as they age (Tornstam, 1997). However, the quantity of social relationships is independent of the significance of social relatedness in one's life. There are several reasons to believe that being connected with others, being socially engaged, are more crucial for older adults than for younger ones.

First and foremost, social support is particularly valuable in times of stress. Being old is inevitably accompanied by a range of life stressors such as biological frailty and the constrained daily activities associated with it, limited financial means, and the continuous loss of close social relationships through illness and death. Thus, social resources should be used to create a buffer against these stressful life circumstances for older adults. Second, older adults may have goals that are different from those of younger adults, and are most effectively achieved through maintaining positive social relationships. This view derives from a well-established theory called "socioemotional selectivity theory," developed by Laura Carstensen (1991). According to this theory, older and younger people have different social motivations based on their varying appraisals of the time they have left. As older people feel that their time on earth is limited, their focus is more likely to be on the here and now, with relatively little interest in the future, unlike their younger counterparts. This involvement in the present results in an emphasis on maintaining pleasant emotional states, which necessarily involves quality social relationships with one's inner circle of close friends and family members, since these relationships are reliable sources of positive and meaningful emotional experiences. Thus, in old age, close-knit relationships with people

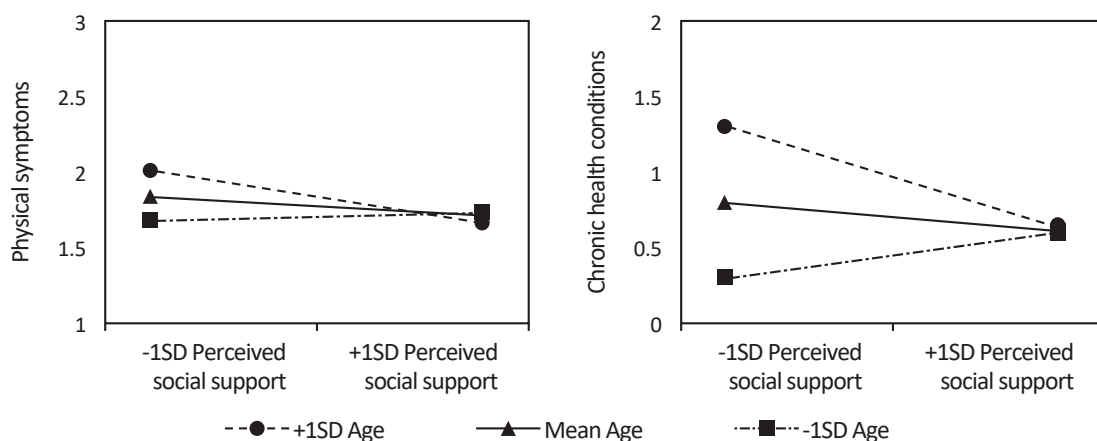
with whom one can exchange support and affirm one's sense of self become ever more important.

## Having positive social relationships is more important for older people than for younger people

A few years ago, I and my colleagues conducted a study to test socioemotional selectivity theory among Korean adults (Choi et al., 2018). We wanted to examine whether feeling that one is connected with and supported by close others becomes more important as people age. Using two samples of Korean adults aged 20 to 69, we examined the association between a person's perceived social support (the degree to which people believed they were getting support from close relationships, including friends, family, and significant others) and their physical health, which is an excellent proxy for quality of life. The results were very clear. Perceived social support was more predictive of physical health for older adults than for younger ones. Specifically, perceived social support proved to be beneficial for those in their late 50s and older, not so much for those in their 40s, and there was virtually no relationship between perceived support and physical health in adults in their 20s (see Figure 1).

**Figure 1**

*The relationship between perceived social support and physical health across different age groups*



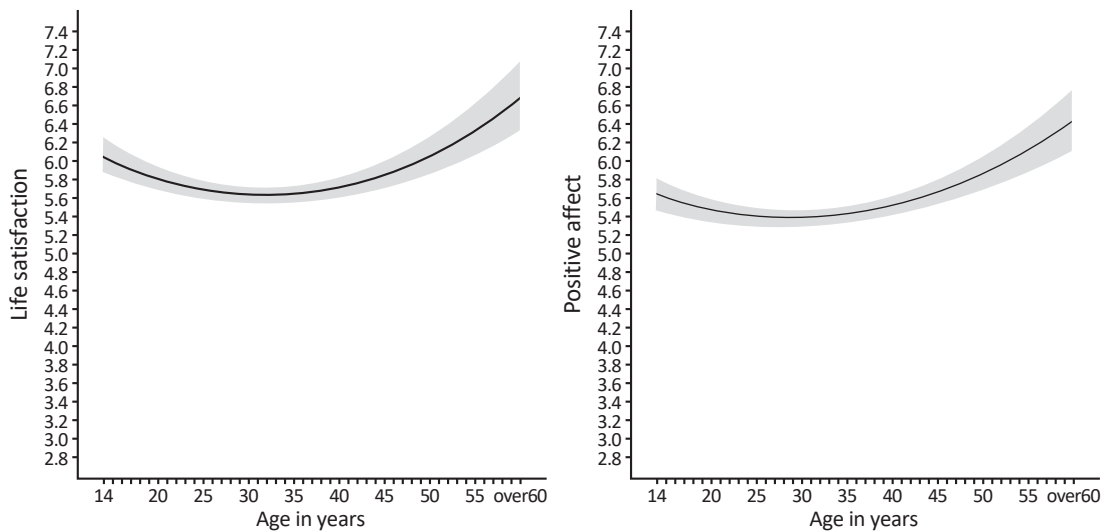
*Note.* -1SD Age = 28.11 years, Mean Age = 43.22 years, +1SD Age = 57.83 years. Adapted from "Social relatedness and physical health are more strongly related in older than younger adults: Findings from the Korean adult longitudinal study," E. Choi, Y. Kwon, M. Lee, J. Choi, & I. Choi, 2018, *Frontiers in Psychology*, 9(3), p.6. Reprinted with permission.

Another piece of evidence came from a study in which we found that the personality trait known as “agreeableness,” essential for the formation and maintenance of social relationships, plays a particularly critical role in old age. Agreeableness is found to have positive associations with features that foster social relationships, including a tendency to cooperate, forgive, and avoid quarrelsome behavior. Generally speaking, agreeable individuals tend to choose a more adaptive strategy in interpersonal conflicts, and are therefore more likely to be satisfied with life. This positive relationship between agreeableness and happiness was found to be more pronounced among older adults than younger people.

To put this in the context of age differences in well-being, in our study we discovered that the well-established U-shaped relationship between age and well-being was driven by the personality trait, agreeableness. To the surprise of many, ample research has found that older people are happier than younger adults. Despite a popular “rosy view” of youthful years, studies from diverse countries around the world have documented that well-being increases after the age of 50 (Stone et al., 2010). A study I conducted recently with colleagues (Kim et al., 2022) established that this pattern of well-being across different age groups was replicated with a large sample of South Koreans (N = 10,456) aged between 14 and 75 years. Among South Koreans too, it appears, older adults are more satisfied with life and experience greater positive emotions than younger people (see Figure 2).

**Figure 2**

*Age differences in the well-being indices of life satisfaction and positive-negative affect*

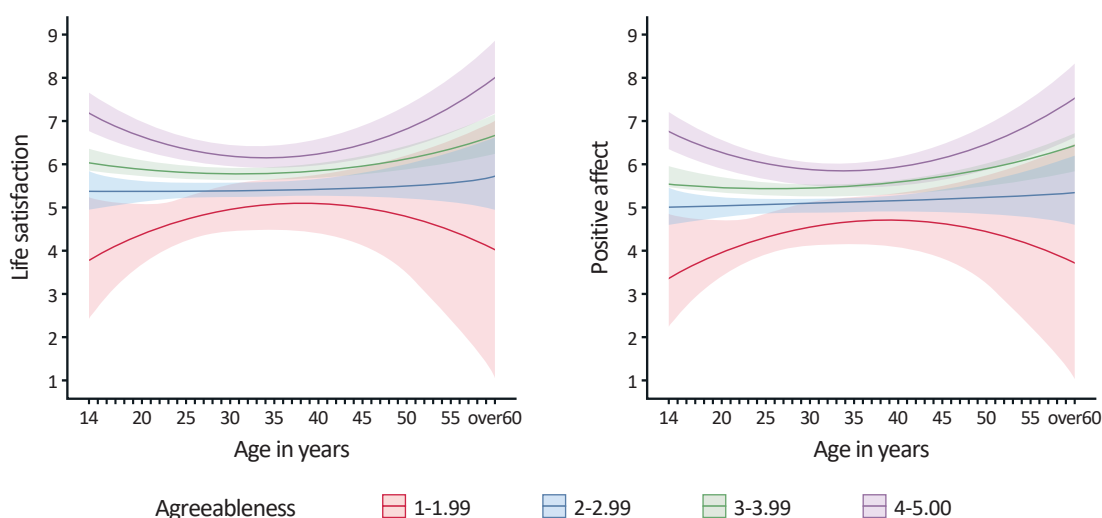


Interestingly, we found that this U-shaped relationship between age and well-being depended on individuals’ “agreeableness.” It turned out that it was those older adults

who were more agreeable than others that fared better than their younger counterparts (see Figure 3). However, those older adults who were not agreeable were not particularly happier than the younger adult groups. That is, it appears that those older adults who were able to form and maintain gratifying relationships with the help of their predisposition to be agreeable and harmonious in social interactions were likely to enjoy as much satisfaction and pleasant experiences in their lives as healthy young adults, if not more. This, again, suggests to us that in the later stages of life, feeling validated and loved in one's intimate relationships is critically important for leading a happy life.

**Figure 3**

*Agreeableness moderating the relationship between age and the well-being indices of life satisfaction and positive affect*



## Encouraging and facilitating social participation by older adults can be an effective strategy for protecting their mental health

But older adults have particular difficulties fulfilling their needs to belong and connect and get the satisfaction from interacting with others. The deaths of close others (e.g., friends, relatives, spouse), poor health, an ageist societal atmosphere, and retirement from the workplace, all challenge older people's ability to connect with others. Retreat from the workforce, in particular, strips older adults of the social group membership and social identity which are a basis for well-being and health. However, the workplace is not the only context in which one can feel a sense of belonging. There are non-work related social

groups that involve leisure activities, physical exercise, and religious activities, to name just a few. In fact, previous studies have found that retirees who were able to maintain multiple group ties during their transition to retirement had better health and a far lower risk of early death (Steffens et al., 2016).

Korean older adults are no exception. We analyzed 4,751 community-dwelling older adults aged 60 and above from the Korean Retirement and Income Study (KRIS) and found that social participation in diverse settings was indeed protective of mental disorder such as depression (Choi et al., 2021). Specifically, the analysis showed that participating in volunteer work, making donations, and engaging in social activity (e.g., hobby club, sports club, community circle, civic organization, political party, religious communion, or academic association) at least once a year significantly lowered the probability that an older individual would develop depressive symptoms. The more frequently older adults participated in these activities, the less likely they were to be depressed. In addition, engaging in multiple social activities was even more beneficial. For one thing, people get to interact with diverse groups and build supportive relationships with one another. In particular, feeling that one is emotionally supported is well-documented to be a highly effective buffer against depression. Overall, perceived emotional support is known to be superior to instrumental support (i.e., help with daily chores around the house), which may violate one's autonomy and cause feelings of helplessness. Equally importantly, occupying multiple roles enables older adults to find meaning through a sense of identity as a valuable member of a social group, which results in enhanced self-efficacy and self-esteem (Lemon et al., 1972).

The take-home message from these studies that analyzed the benefits of social participation for older adults is that even though relationships in these social organizations are not typically considered as strong as ties with family or relatives, they can still serve as social networks that are supportive and emotionally fulfilling. That is, forming novel relationships after retirement through diverse groups is not only possible but may be a valuable avenue for older adults to renew a sense of connectedness with the world. Contrary to the socioemotional selectivity theory that emphasizes the importance of long-standing close-knit social relationships for older people's well-being, older individuals can still actively seek and form new relationships in their neighborhoods and communities and have satisfying relationships. Also, with the help of advances in digital technology, there may be greater opportunities for older adults to connect with others who share their interests and goals than in the past. It is important to keep in mind that, given the opportunity, older adults can gain vitality through social relationships. It is up to us to provide these opportunities, because we can.

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# Dignity and human rights in healthcare services for older persons : a “why & how” for clinicians

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## **Abstract**

The world is undergoing rapid population ageing. With this demographic transition, healthcare for older adults needs a paradigm shift to become more inclusive and rights-based. Dignity is a multi-dimensional concept comprising social inclusion, social recognition, independence, justice, respect, equality and enjoyment of human rights. Professionals in the field of geriatric healthcare are uniquely positioned to incorporate and integrate clinical strategies based on dignity, and advocate for social/health policies to protect the human rights of older persons. However, dignity is often considered to be an abstract and philosophical entity, and as a result, it receives insufficient attention in clinics and research. This can serve as a major threat to rights-based and person-centred care for older people,



who already suffer vulnerabilities such as frailty, neglect, social isolation, multi-morbidities, depression, dementia, elder abuse and ageism. The ongoing COVID-19 pandemic has further widened health inequalities for older people. Hence, ensuring dignity, respect, human rights and autonomy in routine clinical care for older people assumes paramount importance.

Against this backdrop, this article considers the definition of dignity and how it relates to all aspects of care for and among older people, with special reference to clinical syndromes that include frailty and dementia, and the need for evidence-based care delivery to avoid violations of an individual's dignity. The authors also highlight intersections of human rights and dignity, and outline clinical recommendations for dignified healthcare for older persons.

Dignity in mental health care and social support – a complex and hard to define concept – is one of many dimensions of human dignity. It is the basis for an ethical approach to promoting well-being as well as addressing a mental health problem. When dignity in mental health care is promoted – including protecting against stigma, discrimination, violence against older adults, elder abuse and neglect – the chances of a better clinical outcome are higher. In summary, the dignity principle in mental health care sustains the legal and ethical framework to support older adults who may have lost their autonomy and independence as a result of mental health problems and other co-morbidities associated with old age and the ageing process (Saxena & Hanna, 2015; United Nations General Assembly, 1966).

Besides the fact that the majority of older adults are in good health and are satisfied with their quality of life, there are also numbers of older adults living with co-morbidities, depression, dementia and other progressive illnesses (Ferri et al., 2005; Jacobzone, 1999). Provision of good quality care is important not only to assure optimal autonomy and independence (Levenson et al., 2005; Lothian & Philp, 2001), but also to preserve older persons' basic human rights. We are aware that independence and autonomy are regarded as Western concepts and should be used carefully, especially in transcultural settings. Furthermore, autonomy in a mental health setting, but also in other contexts of vulnerability, is often an ideal that can become a fallacy if structural factors are ignored; in some settings, the ideal of autonomy should be reframed as interdependency (Caplan, 2014; Smebye et al., 2016). All in all, and despite the growing critique of normative interpretations and applications of autonomy in healthcare generally (and more specifically in the context of ageing), scholars do recognize that respect for autonomy is a deeply valued social concept that may best be modified rather than discarded. Critical scholars of autonomy, particularly in the context of ageing discourse, have therefore called for

a broad re-conceptualization of autonomy as it relates to caregiving and care receiving. In this process, a view of autonomy may be developed that does not place dependency in antithesis to autonomy, that acknowledges the social context in which an individual is embedded and allows for meaningful recognition of the diversity of autonomous expression that exists in the context of everyday lives (Sherwin & Winsby, 2011). In fact, this paper will argue, dignity transcends independence and autonomy.

Increased longevity is the result of a significant decline in mortality rates across the whole age spectrum, and many nations have often not taken this into account in their long-term planning. As a result, older adults in the future may face many more challenges than today's older populations (Hall et al., 2014; Jacobzone, 1999). In this context, failure to include the principle of dignity in mental healthcare planning may lead to the development of bad mental health policies, programs, and services. That is why so many analysts continue to highlight age discrimination, poor access to health delivery and social care as problems facing older people (Gallagher et al., 2008).

With this as background, this article highlights varying dimensions of the concept of dignity, and how it can be incorporated in healthcare services for older people, and discusses the evidence backing the efficacy of dignified healthcare, and ways forward.

## **Definition: What constitutes dignity?**

The concept of dignity is now central to many worldwide policies aiming to support the delivery of care, but there is often no single agreed definition of dignity in care. Despite this, people are usually able to recognize when an individual's dignity is violated, and also when dignity in care is enhanced. We therefore require the concept to be clarified in its component parts, so that caregivers and care receivers can have a shared understanding of what is being referred to when we talk about dignity in healthcare (Gallagher, 2011; Nordenfelt, 2003).

A good working definition of dignity is that it refers to being of value or having worth (Gallagher et al., 2008). It is a sign of respect.

The first Article of the United Nations Universal Declaration of Human Rights states, "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (United Nations General Assembly, 1948). The Constitution of the World Health Organization states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (World Health Organization, 1948, p. 51).

A human rights framework that specifically addresses the issues of older people with mental health problems still needs to be developed. This is necessary because of the vulnerability of this population by virtue of societal ageism, stigmatization and exclusion, as well as the disability and dependency which mental illness in old age may confer. The following values should underpin such a human rights framework (World Health Organization & World Psychiatric Association, 1997):

- Independence: Older adults with mental health problems have the right to contribute to society and to make their own decisions on matters affecting life and death. However, those who are not able to live independently have the right to rely on others, for instance, on community help.
- Safety: Older adults with mental health problems have the right to live safely, with adequate food and housing, free of violence, abuse, neglect and exploitation.
- Care and treatment: Older adults with mental health problems should benefit from family and community care and protection, and have access to healthcare to maintain or regain their optimum level of function and well-being and prevent or delay deterioration.
- Confidentiality: Older adults with mental health problems have the right to expect that information about them should be treated confidentially. The degree of any breach of confidentiality must be proportionate as well as necessary. This is culturally sensitive.

During the twentieth century, dignity developed as an issue for physicians and medical researchers. In more recent debates, dignity has been invoked in relation to the bioethics of human genetic engineering, human cloning, and end-of-life care. In June 1964, the World Medical Association issued the Declaration of Helsinki, whose Article 11 says, "It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects" (World Medical Association, 2013, p. 4). The Council of Europe, on 4 April 1997, at Oviedo, approved the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. The Convention states, "Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine" (Council of Europe, 1997, p. 36).

As a consequence of these statements, good health and a life of good quality are now recognized as fundamental human rights, respecting the human dignity of people in all age groups, and including those with mental disorders. All people have the right of access to a range of services that can respond to their health and social needs. These needs

should be met appropriately for the cultural setting, and in accordance with scientific knowledge and ethical requirements. In consequence, governments have a responsibility to improve and maintain the physical and mental health of older people, and support their families and their carers, by the provision of health and social measures adapted to the specific needs of the local community (Katona et al., 2009).

Health and social professionals should act at all times to respect the dignity and personhood of older adults with mental illness. The following principles should guide their practice (Katona et al., 2009):

- Respect for autonomy: This means to respect an individual's right to self-determination and the decisions they make regarding their health and social care, provided they have the capacity to do so. The aim of mental health interventions for older adults is to preserve and enhance their personal autonomy.
- Beneficence/non-maleficence: Beneficence considers the potential benefits arising from a therapeutic action, balancing these against potential risks. Non-maleficence refers to not causing harm.
- Justice: This refers to the need to ensure equitable distribution of resources and to treat all patients equally.
- Veracity: Clinicians should be honest with patients, who have the right to know (or not to know) their diagnosis and be given accurate information when requested.

Human dignity can be violated in multiple ways, such as humiliation, instrumentalization or objectification, degradation and dehumanization. All these kinds of violations can be present during clinical activity. If healthcare professionals can keep this in mind during every encounter with an older adult, then dignity is likely to be maintained and enhanced. Dignity is often included in the Code of Practice for professional groups, including nurses (International Council of Nurses, 2012) and doctors (World Medical Association, 1995).

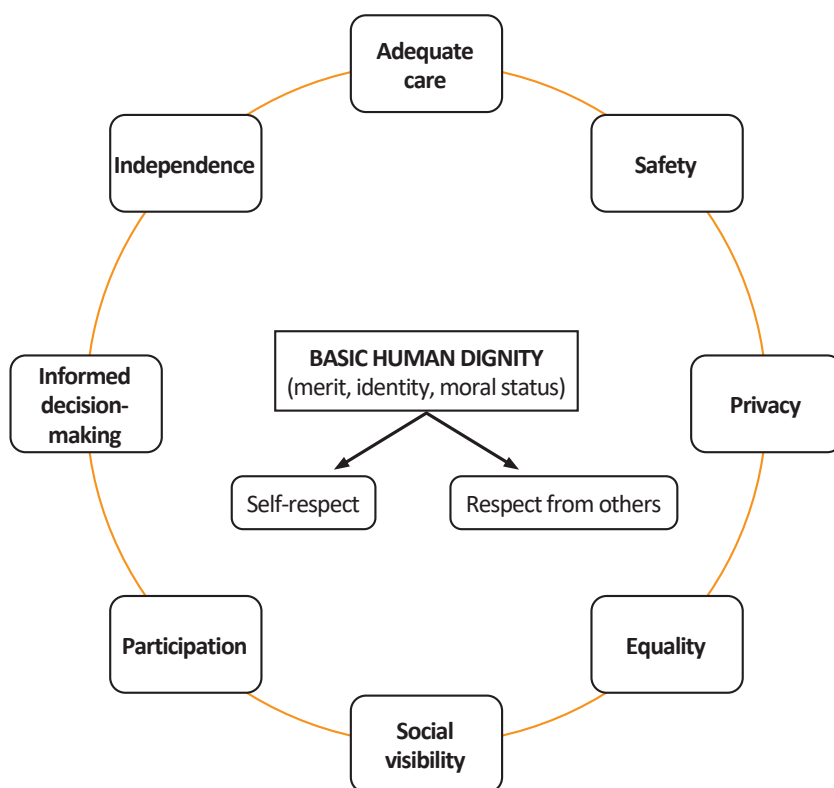
Research has shown that a sense of personal dignity flows from two components: one internal, "how I see myself," and the other external, "how others see me" (Mann, 1998). These two dimensions reinforce each other. Therefore, it is essential for healthcare professionals to approach an older adult empathetically – as an individual human being – while also recognizing their specific age-related physical and mental health needs. The temptation to stereotype older adults as part of a single homogenous group takes away their individuality, contributes to the increased stigma associated with older age, and increases the risk of denying them their dignity.

In a previous publication, Banerjee, Rabheru, de Mendonca Lima, and Ivbijaro (2021)

discussed the intersections between the human rights of older people and dignity-based healthcare, as well as how ageism and elder abuse compromise dignity and quality of life. The authors highlight that dignity is a multi-dimensional construct comprising self-respect, social acknowledgement, independence and privacy. Figure 1 reflects the same (Banerjee, Rabheru, de Mendonca Lima, et al., 2021, p. 3). An international Convention for the rights of older adults is needed, which can set global standards and regulations for dignified healthcare.

**Figure 1**

*Factors determining human dignity*



*Note.* Adapted from “Role of dignity in mental healthcare: Impact on ageism and human rights of older persons,” D. Banerjee, K. Rabheru, C.A. de Mendonca Lima, & G. Ivbijaro, 2021, *The American Journal of Geriatric Psychiatry*, 29(10), p.3. Reprinted with permission.

Dignity debates have several shortcomings that need to be addressed in order to advance the discussion. First, certain directive recommendations have been formulated as what Ridge calls “impassioned beliefs”: a number of “shoulds” are provided without adding concrete measures for change (Ridge, 2014). Second, dignity is often conceived of as interpersonal, although much of what constitutes dignity needs to be seen as structural

(Golder, 2015). Third, solutions to a lack of dignity are often seen as emotional work (e.g., empathy and love) which, although important, can sometimes be reductionist: older people are described as passive victims, and the social origins of diseases are ignored, or reduced to the status of biomedical problems (Breithaupt, 2017).

Although we are not able to resolve these critical points in this article, we argue that more research is needed in this regard.

## Why should professionals care?

Many older adults want services that are reliable and dependable, easy to access, with competent staff that are sensitive and recognise diversity. When they have health needs, many older adults like to have their needs managed in a collaborative way (Levenson et al., 2005). This requires a supportive community. Some older people want to be close to their families if they need to receive treatment in hospital. We need innovation for this to be achieved, taking the patient's view into account; new technology may have to be adapted for use in an ethical and responsible way.

Many older persons want healthcare professionals to care for them with empathy, treating them as individuals and forming human bonds (Sinclair et al., 2016). There is growing evidence that clinical empathy – the medical professional's cognitive understanding of patients' emotions, combined with emotional attunement – directly enhances therapeutic efficacy (Halpern, 2003). The teaching and encouragement of empathetic behavior must be a priority among healthcare professionals caring for older persons (Lee, 2014).

In particular, health and social care professionals need to receive special education and training in dignified care for older adults with mental disorders. Mental health education for professionals, caregivers, and the lay people in old age will minimize the burden of mental disorders. At both undergraduate and postgraduate levels, all health and social care professionals should receive training in a clinics and skill-based curriculum on mental health issues in old age. Such a curriculum should include the significance in old age of the interdependence of mental, physical and social factors, and information on the prevention of ill-health, and health promotion activities that include recreational, cultural and spiritual issues (World Health Organization, 1998).

Training opportunities in old age mental health should also be available for specialists. These specialists should demonstrate the ability to deliver appropriate, good quality and cost-effective physical, psychological and social interventions in the management of mental illness among older people living in the community or in residential or hospital settings. They should demonstrate an understanding of the social, economic and cultural changes

associated with the ageing process, taking into account cultural, spiritual and ethnic issues in the recognition, assessment, diagnosis and management of mental health problems in the older person, and know how to manage the promotion of the person's dignity. They should have the ability to run a multi-disciplinary community-oriented service for older people with all forms of mental health problems that ensures equity of access to care, and be able to work effectively and efficiently in different settings. Specialists should be able to evaluate stress in carers, determine what is causing overload, and demonstrate the ability to organize appropriate support packages. In this context, specialists should demonstrate an understanding of all aspects of elder abuse and the ability to recognize and manage elder abuse in a range of different settings (Gustafson et al., 2003).

Banerjee, Rabheru, Ivbijaro, and de Mendonca Lima (2021), in "Dignity of older persons with mental health conditions: Why should the clinicians care?," address how principles of human rights, dignity, equality and respect might be incorporated into healthcare interventions for older people with mental health disorders. Since they are more vulnerable to health inequalities, social isolation and discrimination, tailored care needs to be ensured at all levels of healthcare and policy interventions. Sensitization and training of professionals involved in geriatric care related to dignity-based services form the core of such an approach.

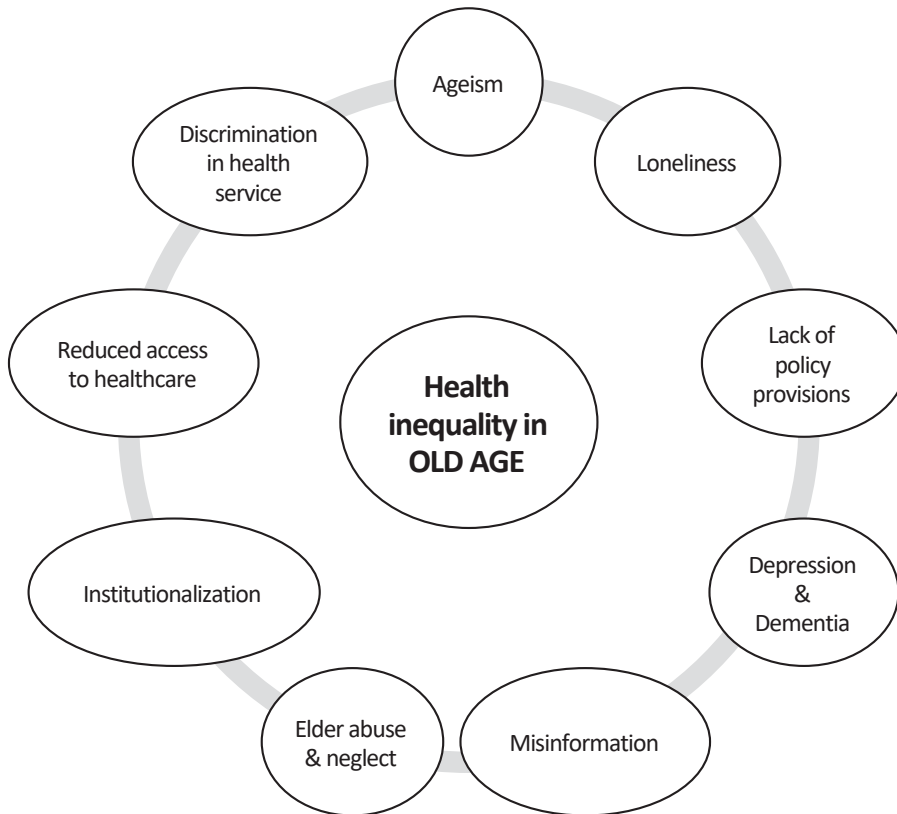
## **Discrimination against older adults with mental health conditions**

All persons with a mental disorder (or who are being treated as such persons) must be treated humanely and with respect for the inherent dignity of the human person. It therefore follows that the stigmatization of people with mental disorders must be countered wherever it occurs. However, stigmatizing is common human behavior; it is pervasive and subtle in its effects, and difficult to counteract without clear and conscious strategies. Since stigma against old age – independent from that against mental disorder – also occurs in many (although not all) societies, there is a "double jeopardy" for older people with mental disorders, and both issues need to be addressed in anti-stigma strategies for this age group. Counteracting stigma and discrimination is a duty of governments, NGOs, services, patients' organizations, families, and the general public. To be effective, they need to work in partnership. Action to end the stigmatizing of, and discrimination against, older people with mental disorders, should be a priority of all, to achieve the state of physical, psychological and social well-being defined by the Constitution of the WHO. Such action should form part of the promotion of good mental health in professional training and public education, and should be a major component of all levels of a health and social care program (World Health Organization, 2002).

## Effects of the COVID-19 pandemic

**Figure 2**

*Dimensions of health inequalities in older people*



*Note.* Adapted from “Human rights and mental health inequality among older persons: Urgent need for a global convention,” D. Banerjee, G. Ivbijaro, C.A. de Mendonca Lima, & K. Rabheru, 2021, *In WFMH World Mental Health Day 2021 Educational Material*, p.67. Reprinted with permission.

There are multiple dimensions to older people's human rights as shown in Figure 2 (Banerjee, Ivbijaro, de Mendonca Lima, et al., 2021, p. 67); they include the rights to freedom and health as well as reproductive/sexual rights. The COVID-19 pandemic has indeed been an eye-opener in many ways: the biopsychosocial marginalization of older persons has surfaced, revealing an “invisible human rights crisis” (D’cruz & Banerjee, 2020). Older people are already susceptible to the neurobiological effects of the virus: morbidity, mortality and respiratory complications. Lack of dignified healthcare, neglect, discrimination in healthcare, and elder abuse are the predominant ways in which older persons are deprived of their rights. But the COVID-19 pandemic has impacted on social aspects of older people's lives in various ways, as depicted in Table 1.



## Table 1

### *Psychosocial toll of the COVID-19 pandemic on older persons*

- Increased fear of infection because of being a vulnerable population
- Fear of dying alone
- Social isolation
- Loneliness
- Grief, and “survivor’s guilt”
- Worsening of pre-existing dementia and depression
- Anxiety
- Limited access to healthcare and social support
- Stigma and ageism
- Rise in elder abuse (especially in institutions)
- Prone to misinformation
- Restriction of mobility and autonomy

The WHO data reveal that one in six individuals worldwide over the age of 60 was the victim of abuse in 2021; however, cases are under-reported. The rates have increased during COVID-19, especially in nations with increased population ageing (World Health Organization, 2021). The serious “social evil” of elder abuse arises from ageist stereotypes (i.e., what we think), prejudice (i.e., how we feel) and discrimination (i.e., how we act). The need to focus on dignity and autonomy in healthcare is vital to fight ageism and support dedicated care for older persons (Banerjee, Rabheru, de Mendonca Lima, et al., 2021). Ensuring age-friendly environments, promoting long-term and integrated geriatric healthcare, and combatting ageism resonate as messages for the UN International Decade of Healthy Ageing 2021-2030 (World Health Organization, n.d.). These actions can only be facilitated by engaging older persons, giving them a “voice,” connecting interested stakeholders and care providers, and, finally, promoting research into ageing.

## Dignity and social determinants of health – the intersections

Mental well-being is an asset of individuals, communities and populations, whose value can change throughout the life course, especially in later life. Someone's mental health is affected by a range of determinants throughout life, such as genetic heritage, personal experiences, and the environment in which the person lives.

Social determinants of health are the conditions in which people are born, grow, live, work and age, and are shaped by the distribution of money, power and resources at global, national, and local levels (de Mendonca Lima, 2011). These social determinants are associated with mental disorders by contributing to their onset or course.

### Table 2

#### *Social determinants of health*

- Cultural and spiritual references
- Education and literacy
- Physical environment
- Social status and security
- Financial resources, including income security
- Food and housing security and quality
- Health system
- Justice system, including respect of human rights
- Employment and working conditions
- Leisure and personal development
- Spiritual development
- Discrimination and stigma
- Inequalities
- Social, political and physical exclusion and marginalization
- Violence, abuse, neglect, and abandonment

Some social determinants may play a role as risk factors for mental health problems (e.g., unemployment, poverty, inequalities, stigma and discrimination, poor housing, poor early

years, violence, abuse, drug and alcohol abuse, poor general health, and caring duties), while others may be protective factors (e.g., social protection, resilience, social networks, positive community engagement, positive spiritual life, hope, optimism, good general health, good quality of family interactions, and positive intergenerational relationships).

By acting on social determinants of health, it is possible to contribute to promoting the dignity and subjective mental health and well-being of older people, building the capacity of communities to manage adversity, and reducing the burden and consequences of mental health problems. Disadvantages due to mental health problems in old age damage the social cohesion of communities and societies by decreasing interpersonal trust, social participation, and civic engagement (Searight & Gafford, 2005). Disregarding these social determinants in healthcare can lead to several inequalities as in Figure 2 (Banerjee, Ivbijaro, de Mendonca Lima, et al., 2021, p. 67). Aptly, in 2021, the World Federation for Mental Health (WFMH) set the theme for World Mental Health Day as “Mental Health in an Unequal World.” Older people are one of the key populations vulnerable to the inequalities which can lead to biopsychosocial adversities (Banerjee, Ivbijaro, de Mendonca Lima, et al., 2021).

## Ensuring dignity in sheltered housing and nursing care homes

Although, in general, older adults prefer to remain at home, it is inevitable that some will require care in sheltered, residential, and nursing care homes. In these circumstances, research shows that older adult residents want a well-trained workforce, sensitive to their needs, providing care in a place that is safe, homely, and clean. They want reliable workers and positive attitudes amongst staff (Levenson et al., 2005).

Similarly, research shows that many older adults prefer to die at home, but this is not possible in many cases. If an older adult is to die in any supported settings other than their own home, it is important for them and their family to be involved in planning this. Some of the things that older adults find important to prepare for in these circumstances are pain control, good management of any symptoms that they are experiencing, avoidance of inappropriate prolongation of life, feeling that they still have control as individuals, and closeness to loved ones. Religious, spiritual and cultural values also need to be considered, and incorporated into care planning (Dy et al., 2008; Prendergast et al., 1998).

Older adults in sheltered, residential and nursing care homes ideally want to participate in decisions about their own care, the choice of where they live and their daily routine, including what to wear and eat. More sensibility is needed in order to understand the needs and

desires of people for whom it is difficult to verbalize their preferences, such as in advanced dementia and confusional states. Such approaches generally require well-trained staff who are familiar with older people's life history. Furthermore, older adult residents want good security wherever they are, and to have someone to talk to (Levenson et al., 2005).

When the factors that contribute to dignity in supported accommodation settings in the West were explored, the themes that emerged were those of independence, autonomy, choice, ability to control destiny, and privacy. More specifically, older adults living in such settings wanted to be recognized as individuals who commanded respect, to have the opportunity to talk to other people, and to maintain a good physical appearance. Some studies have suggested that residents' bringing in pieces of their own furniture and household belongings, including photographs, supports the recognition of individuality (Anttonen & Haikio, 2011; Bland, 1999). In some contexts, such as among Canada's Inuit populations (Dawson, 2008), community living takes precedence over privacy. We believe that living spaces need to be individualized, and generalizations need to be avoided.

One of the greatest challenges to care delivery in sheltered, residential and nursing care settings is that of balancing risk management with privacy whilst supporting maximum independence. There need to be environmental, relational and procedural structures in place to ensure that older adults have as much independence and privacy as possible whilst reducing risk, because many people's greatest fear when they enter such accommodation is loss of independence (Baillie, 2009; Leibing et al., 2016).

Some patients will require hospital treatment and care. Patients are more vulnerable to loss of dignity in such settings, and staff should be aware that their interventions can help to promote patients' dignity or lead to its loss. Hospital managers need to play a role in ensuring that the institution promotes dignity, and that staff have the capabilities to provide dignity in care, for instance, by avoiding treating older people like children. Ward design can either support privacy, autonomy, and dignity, or make patients more vulnerable by making it harder to promote individuality (Van der Geest, 2002; Walsh & Kowanko, 2002).

When an older adult is admitted to an in-patient hospital ward, it is necessary to include them in all the decision-making, and the care plan should contain a section on maintaining dignity so that this can be at the forefront of everybody's mind. Issues that should regularly be considered include personal and oral hygiene, ability to interact and communicate, good nutrition and hydration, opportunity to exercise, privacy, and the quality of staff-patient interactions (Stanley & Laugharne, 2011; Wårdh et al., 1997).

In all supported care settings, good staff communication skills are fundamental to the promotion of dignity in older adults, and this can be taught. Patients should routinely be asked how they would like to be addressed, and there should be meaningful interactions

between carers and older adults, in order to avoid social isolation (Caris-Verhallen et al., 1997). Independence and autonomy should be encouraged at all times. Confidentiality and privacy will ensure that the needs of older people are addressed with respect.

Specific considerations for ensuring rights- and dignity-based healthcare for older adults living in assisted facilities and nursing homes are highlighted in Table 3 (Banerjee, Rabheru, Ivbijaro, et al., 2021, p. 5).

**Table 3**

*Ensuring dignity-based care for older people in nursing homes/residential facilities*

- Optimal pain management
- Improving communication within and outside the facility (in-person and digital)
- Respect in daily conversation
- Foster independence in functioning (self-care: choice of living, eating, dressing, etc.)
- Good nutrition and hydration
- Ensure decent physical appearance, personal and oral hygiene
- Healthy interactions with the staff
- Age-friendly environment for mobility and safety
- Supervision for security and prevention of abuse
- Adequate ward design for ensuring privacy and sexual rights
- Group activities, exercise and engagement within the facility
- Prevent loneliness and isolation
- Restrict empirical use of psychotropic medications
- Residential care plan to include principles of dignity
- Involvement in decision-making to the extent possible
- Special care for those with severe mental disorders and dementia
- End-of-life care (avoid unnecessary and painful prolongation of life)
- Dignity therapy for older persons and their families in case of co-morbid terminal illness

*Note.* Adapted from “Dignity of older persons with mental health conditions: Why should clinicians care?,” D. Banerjee, K. Rabheru, G. Ivbijaro, & C.A. de Mendonca Lima, 2021, *Frontiers in Psychiatry*, 12, p.5. Reprinted with permission.

## Homelessness in older people

The proportion of older adults among the homeless population is rising sharply, and is likely to continue to do so, influenced by demographic, economic and social trends in Western societies. For example, in the UK, people aged over 60 years are now more than twice as likely to be homeless than in 2009 (Ryan, 2018). In the US, late baby boomers, born 1954–64, have a higher risk of homelessness than other age cohorts (Culhane et al., 2013), and one-third of the chronic homeless are aged 50 years or over, a number which is likely even higher today (Hahn et al., 2006).

Homelessness goes hand in hand with physical and mental health issues. The older adult homeless are more likely than their housed peers to have chronic conditions, including mental health issues, and face substantial barriers to accessing healthcare (Baggett et al., 2010). Homeless individuals also suffer from geriatric conditions decades earlier than housed older adults, including cognitive or visual impairment, incontinence, and frailty (Brown et al., 2017).

Older homeless individuals often fall between the cracks of government provision because they are not old enough to meet the criteria for the type of social programs they require, or face delays and lack of coordination in the transition of care following a hospital admission. Research shows that stigma is endemic in the way the older adult homeless are treated in hospitals and when they are released back onto the streets with little support (Healthwatch England, 2015).

Not only are older persons who are homeless unable to age in dignity on the streets, but they also have a four times higher mortality rate than those who are sheltered (O’Connell, 2005). Preventing homelessness is essential to promote dignity in the care of older individuals, and ensure equality of health and life expectancy.

## Frailty – a major threat to dignity

Frailty can be defined as “a state of increased vulnerability to stressors due to age-related decline in physiologic reserve across neuromuscular, metabolic, and immune systems” (Walston et al., 2006, p. 3). When facing a health stressor, frail older adults are likely to experience a greater loss in functional ability than their non-frail counterparts, and to have slower and incomplete recovery of their functional status (Büla et al., 2019; Clegg et al., 2013).

Dignity in care is at the core of the management of frail older adults. Frail older adults may have an increase in their dependency level, be more victims of falls, and be more referred

to definitive institutionalization. Traditionally, frailty is considered as irreversible, resulting in stigma, loss of hope, and therefore loss of dignity (Sternberg et al., 2011).

Recent evidence has provided hope in the field of frailty by recommending that a validated screening tool be used to identify adults with frailty earlier. Individuals identified as suffering from frailty should receive specific care to prevent further complications and avoid premature institutionalization. Physical activity training programs that include a resistance training component, and investigation to identify other causes of fatigue and weight loss, are valuable measures (Dent et al., 2017).

Frailty is sometimes accentuated by inappropriate medication use. STOPPFrail (Screening Tool of Older Persons Prescription in Frail adults) can be used to identify prescribed medication that can be stopped safely. The STOPPFrail criteria have been generated using Delphi methodology and can be used by appropriately trained clinicians for medication review. The instrument is not constrained by copyright as long as it is not used for commercial purposes (Lavan et al., 2017).

STOPPFrail highlights four key principles to consider in the review and reduction of medication in adults over the age of 65. The four principles are:

- a) Whether the individual has irreversible end-stage pathology
- b) Whether the individual has a poor prognosis for one-year survival
- c) Whether the individual suffers from severe functional and/or cognitive impairment
- d) Whether symptom control is the priority rather than prevention of disease progression

Keeping these principles in mind during the assessment of an older adult enables clinicians, patients and their family members/carers to take good decisions. The STOPPFrail screening tool has been very reliable (Lavan et al., 2018), as it has also been used in the management of palliative care in frailty (Sevilla-Sánchez et al., 2018).

## Eliminating unnecessary medication

Dignity is also supported by offering evidence-based treatment interventions. Such interventions reduce unnecessary treatments, including unnecessary medication. The most common medications associated with preventable drug-related admissions to hospital, or adverse drug reactions and over-treatment in older adults, are: antiplatelets (including aspirin when used as an antiplatelet); diuretics; non-steroidal anti-inflammatories (NSAIDs); anti-coagulants; opioid analgesics; beta blockers; drugs affecting the renin-angiotensin system; drugs used in diabetes; positive inotropes; corticosteroids; anti-depressants, hypnotics and antipsychotics; calcium channel blockers; anti-epileptics and

nitrates. Patients who are prescribed these medications need to be thoroughly reviewed to ensure that the medication is required, and prescribed in the right dose for the right indication (Zhang et al., 2009).

Prescribers should become familiar with the most up to date guidelines and resources available in the local area in order to provide the best available treatment for patients.

## **Dignity-based care in individuals living with dementia**

In addition to the treatment interventions offered, an important goal in the care of dementia is supporting quality of life, dignity and comfort: this should remain central to treatment and care delivery. Attention should be paid to the activities of daily living, the choice of treatments offered, and the involvement and engagement of individuals and their families to enhance and maintain their dignity (Volicer, 2007).

Intervention programs that include patients' family network are helpful. Family caregivers' health needs should always be considered: positive health in family caregivers may improve the well-being of individuals with dementia and prevent burn-out affecting caregivers' own mental health. This promotes dignity by offering opportunities to care for persons at the place of their choice (Smits et al., 2007).

## **Decision-making capacity**

It is necessary to develop national frameworks to protect people with impaired decision-making ability, in order to respect their dignity in accordance with Article 12 of the UN Convention on the rights of persons with disabilities (United Nations, n.d.). Substitute decision-making (SDM) arrangements range from informal surrogates, through proxies appointed by care recipients when still competent, to those who are appointed by a court. SDM measures and actions must be in the interests of incapacitated persons, and their continuing necessity should be reviewed regularly. Mechanisms should be in place for appeal and review as well as for reporting of alleged mistreatment by SDMs (Katona et al., 2009).

## **End-of-life concerns**

Access to palliative care services should be assured to all in need, to respect their dignity at the end of life. People with dementia often receive sub-optimal end-of-life care. Dignity



also concerns respecting a person's advance directives regarding the withholding of treatment. Attitudes and legal issues regarding assisted suicide/euthanasia vary widely, and practice must adhere to existing laws and ethical codes of conduct (Katona et al., 2009).

## **Optimizing technology and artificial intelligence for dignified care of older persons**

The proportion of older adults in the population worldwide is expected to rise significantly, with a simultaneous reduction in or shortage of caregivers. In order to help patients to continue to live as independently as possible and support some of their daily needs to be met, assistive technologies may be a solution, if their access is assured for all in need (Frennert et al., 2012).

Access to all available local support that can help older adults to maintain independence, autonomy and personal dignity should be assured. This includes the use of simple technology already available in some communities, such as telephones and alarm systems.

Alarms to remember the proper use of medication, to prevent falls, or to call for help, are quite widespread in high- and middle-income countries. The use of robots is becoming possible, but is more restricted.

Robots can assist older adults and their carers in several ways, including with daily household and personal care tasks, the monitoring of behavior and health, and the provision of companionship (Allen et al., 2006; Banks & Banks, 2005; Frennert et al., 2012).

The use of robots to support the dignity and independence of older adults has a lot of potential, but ethical issues and concerns have been raised. These include the reduction of human contact, resulting in social isolation, and the possibility of deceiving older adults with cognitive difficulties (Banks et al., 2008; Sharkey & Sharkey, 2012). On the other hand, technologies often conceived of as “cold,” were perceived as “warm,” because they could guarantee direct access to health professionals without going to hospital, as in the case of monitoring devices (Pols, 2012).

Individuals and their carers should be involved in the decision-making about what kind of robot is needed and what functions that robot will perform in order for robots to be properly deployed as part of a personalized care package to support dignity, whilst acknowledging that robots are not a replacement for human contact (Mordoch et al., 2013).

## Recommendations

- Maintaining older adults' independence as much as possible should always be at the centre of their care plans. This can be facilitated by giving older adults choice and involving them and their caregivers in developing and implementing care plans.
- Balance the need for safety with older adults' independence and well-being.
- All staff caring for older adults must be trained in behavior and communication that maintains the dignity of older adults, and supported to continue these practices in their working lives. They must be aware of older adults' cultural background, and respect any cultural sensitivity, demonstrating empathy, respect and kindness while caring for them.
- Older adults are more likely to be receiving care from different agencies due to co-morbidities, personal care and social needs. Collaborative care is a good model to ensure that all the agencies/caregivers work together, with the older adults at the centre.
- Services that provide care for older adults, such as care homes, sheltered housing and hospitals, should embrace and invest in new technology to help enhance older adults' independence and quality of life.
- Social isolation is a risk factor for poor mental health, and can affect older adults' self-esteem. Health and social care commissioners should ensure there are facilities in place to identify and help older adults at risk of social isolation, such as befriending schemes and day centers.
- There needs to be work with older adults, their caregivers and voluntary sector organizations to ensure that, whenever it is appropriate, older adults are cared for in their homes or in the community with the right package of care, instead of in hospital.
- Special care should be taken to ensure dignity in vulnerable populations (e.g., the very old, women, sexual minorities, older people living with dementia and mental health conditions, homeless individuals, the socio-economically impoverished, and residents of old age care homes and assisted living facilities).
- There need to be sensitization of policy makers and training of healthcare professionals involved with older people at all levels to offer dignified services/interventions.
- Support the global call for a UN Convention for the rights of older people which can serve as a legal scaffolding to protect human rights and dignity in this vulnerable population.

## Conclusion

The human rights and dignity of older people are threatened globally, and it is time we act. “What we permit, we promote.” If we continue the present lacklustre approach towards geriatric healthcare, and reinforce social inertia and neglect, we will not be creating the age-friendly environment we all need. Let us not tolerate the status quo any longer. Let the lives sacrificed by older persons not be in vain by ensuring a positive change for the human rights of every generation of older persons. The UN Decade of Healthy Ageing (2021-2030) highlights enablers who are creating age-friendly environments, combatting ageism, and developing integrated as well as holistic programs to care for older adults (World Health Organization, n.d.). These are only possible if service and policy interventions are based on rights, dignity, respect and autonomy. This article is not exhaustive, but we hope that it generates innovations and ideas for ensuring dignity and equality in the lives of older people. Let us strive to create a world which favors healthy ageing, as ageing is an inevitable fact.

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# Loneliness and the mental health and well-being of older people in the United Kingdom

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*The Campaign to End Loneliness*

The United Kingdom appointed the world’s first minister for loneliness as part of a central government strategy on loneliness in 2018 (HM Government, 2018). The Campaign to End Loneliness had already been active for a number of years before this; our organization was founded in 2011 to build an evidence base on loneliness, develop the community of organizations who care about this issue, and make the case for action.

Our organization was set up to look at loneliness amongst older people, building on concerns about the social isolation that many older people face, particularly the “older old” – people in their 80s or 90s who may have been bereaved, may be in poor health and have relatively few social contacts. However, it has become clear that loneliness is an issue that people can face at any age, and in general, “younger old” people are in fact the least likely to be lonely. This shows the importance of targeting work at those who need it most, rather than using broad generalizations about age groups.

The UK government’s loneliness strategy has shone a spotlight on this issue and encouraged research into the nature and causes of loneliness, and action to find solutions. In this article, we will describe some of our recent work to build a practical evidence base about loneliness.

We start with a more in-depth look at the psychology of loneliness, and the ways we can use an understanding of this psychology to better help people who are lonely. This informs our analysis of the different services and policies that need, in our view, to come together to create a framework for tackling loneliness effectively. Finally, we look at the impact of the pandemic on loneliness in the UK and what it perhaps teaches us about the nature of loneliness.



## The Psychology of Loneliness

Loneliness is an emotional state that many people are familiar with. Understanding how psychological approaches can help ease feelings of loneliness and shape our response can help us improve support for older people who are lonely.

Our report, *The Psychology of Loneliness: Why it matters and what we can do* (The Campaign to End Loneliness, 2020b), brings together our consultations with policy makers and organizations who work with older people, and the views and experiences of the older people with whom we spoke.

Our research demonstrated that we know a lot about the factors that can lead to older people feeling isolated and excluded, and the life events that can contribute to or trigger loneliness in later life. But we know less about the “internal” factors that can shape someone’s experience of loneliness and cause loneliness to become more severe.

### *Why the psychology of loneliness matters*

People use words like anxiety, fear, shame and helplessness to describe how loneliness makes them feel (see Figure 1). These powerful emotions can influence how people behave. They can make people wary of social situations or perceive interactions with others more negatively.

**Figure 1**



How people understand why they are lonely can also make a difference to their experience of loneliness. Loneliness can become chronic if it is seen as something we cannot change. Believing that loneliness is part of who we are, and that we are to blame for it in some way because our relationships are not what we would like them to be, can make loneliness harder to shift.

If loneliness is considered an expected part of becoming older, either by the person themselves or the society in which they live, it can become a self-fulfilling prophecy, and make loneliness in later life more likely.

Whilst we don't know how these factors influence each other, we can see that psychology matters in our understanding of loneliness. And we need to draw on this, along with what we already know about the social and structural influences on loneliness, when we develop support for people who are lonely.

## ***Psychological approaches***

There is evidence that cognitive behavioural therapy (CBT), mindfulness and positive psychology can reduce loneliness in later life (see *The Campaign to End Loneliness, 2020b*, pp. 22–25).

These three approaches share key principles. They identify the automatic negative thoughts and feelings loneliness provokes, which can become overwhelming over time and influence behavior. They use specific techniques to challenge these patterns and replace them with more manageable and positive ways of responding.

In practice, we found several examples of these approaches already being used (e.g., psycho-educational courses to help people prepare for later life transitions, such as the Transition in Later Life Programme, supported by the Calouste Gulbenkian Foundation), drawing on a mix of techniques to suit the person and their circumstances. When delivered by a trained practitioner, they allowed time for reflection and support to identify a meaningful response for lonely clients.

Using the information in our report, we urged organizations to identify the existing use of psychological approaches in their work, design future programs explicitly to include psychological approaches, and take steps to evaluate their impact on loneliness.

In our view, this focus can help to identify which factors, or combination of factors, are effective in reducing loneliness, and for whom, and further develop the evidence base for loneliness interventions.

## What we can do

The insights of psychology can be used to tackle loneliness in three key ways.

**Public campaigning.** Public campaigning can create awareness of how loneliness influences thoughts, feelings and behavior, and how this can affect our relationships over time. People perhaps need help to understand that social relationships need to be nurtured over the life course.

**Group activities.** People organizing group activities for older people, including those running support services, need to consciously build an understanding of psychological and emotional barriers to engagement while they are developing services and training staff and volunteers. Support workers need to be helped to understand that psycho-education can help people manage the life events and transitions which are known as risk factors for loneliness (e.g., bereavement and retirement).

**One-to-one psychological support.** For a smaller group of people with chronic loneliness – which may be part of a complex set of problems – one-to-one psychological support can help. This can be particularly relevant for those seeking support following a bereavement which has triggered feelings of loneliness, or for those with mental health problems.

Our report shows how psychological approaches can help with tackling loneliness. Support for loneliness can be better tailored, and more effective, if it recognizes both the internal and external aspects of a person's experience of loneliness.

## The Promising Approaches Framework

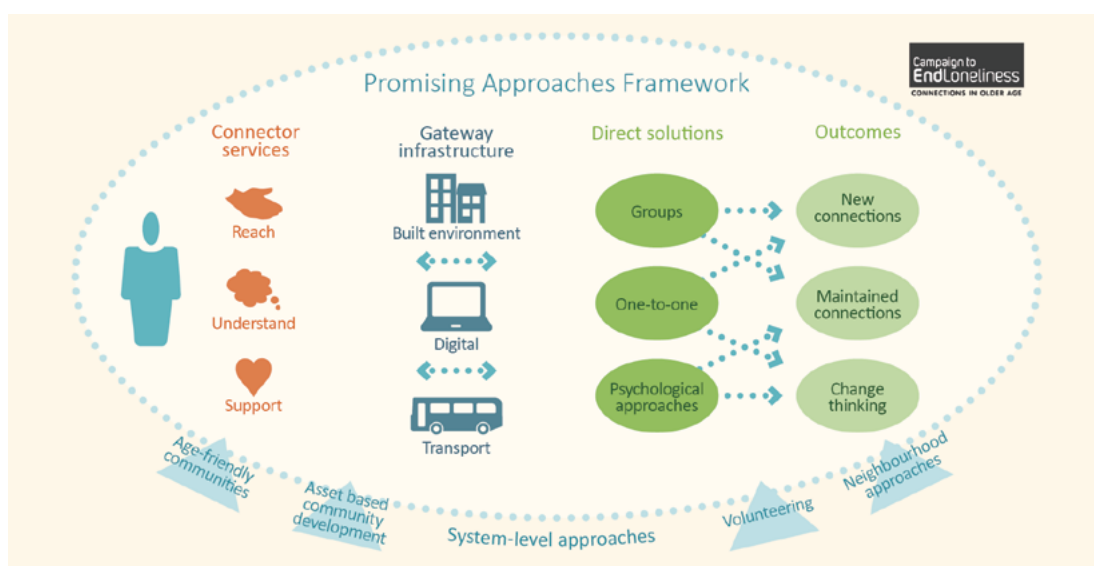
Our 2015 Promising Approaches publication (Age UK & The Campaign to End Loneliness, 2015) set out a framework for understanding different approaches to addressing loneliness, and how they can work together in a community to create an effective response to individuals' experience of loneliness. This framework was built around an understanding of the three central mechanisms for addressing loneliness which De Jong Gierveld and colleagues (2011) extrapolated from the definition of loneliness proposed by Perlman and Peplau (1984), and which was adopted by the UK government (HM Government, 2018; Scottish Government, 2018; Welsh Government, 2020).

These mechanisms are:

- Maintaining and improving people’s existing relationships
- Supporting people to develop new relationships
- Changing how people think and feel about their relationships

Our 2020 Promising Approaches Revisited publication (The Campaign to End Loneliness, 2020a) updated this framework to reflect the approaches which are now being adopted in communities to achieve these three ends (see Figure 2). Our framework is grounded in a universal understanding of loneliness, and so it can be applied to work on loneliness across all ages. However, the approaches we showcased in our report relate mainly to old age. Living Together with Dementia, for example, aims to improve the quality of life and mental health of couples living with dementia through couple-focused psychosocial interventions. Late Spring is a bereavement support group initiated by Age UK Oxfordshire. Middlesbrough Ageing Better Outreach Project provides holistic person-centered support to older adults experiencing loneliness and social isolation.

**Figure 2**



In relation to other age groups, the mechanisms through which the approaches are delivered, the language used to describe them, and the settings in which they are established, should be applied appropriately. For example, in relation to working-age populations (increasingly up to the age of 70 and over), the workplace is likely to be a significant focus of delivery. Our framework is designed to be used by some of the many people and organizations working on the issue of loneliness.

**Local councils and health authorities.** For strategic bodies such as local authorities and health authorities, our framework sets out the different categories of action that are needed in each community. Strategic bodies can use the framework to think about what approaches are in place in their community, and to identify gaps. Most communities will already have a range of approaches in place under each of the categories in the framework. The key question is whether these are optimally designed for impact on loneliness. For example, by building an understanding of loneliness and the potential needs of lonely individuals into outreach schemes and social prescribing programmes (which health professionals can use to refer people for a variety of non-clinical services), they can form a vital part of the community response to loneliness. Similarly, in most areas, there are community groups and activities which are already open to everyone, but they may not be known to front-line staff working with lonely individuals, and these community groups may need additional support to provide the kind of environment in which lonely people can feel comfortable.

Other services already take a place-based (neighborhood) approach to addressing challenges, or work to encourage volunteering. Again, integrating these ways of working into an overall strategic approach to addressing loneliness, and forging links across different parts of the system, will enable communities to build an effective “ecosystem” to address loneliness in the round.

**Organizations delivering interventions.** Our framework can help identify where their work fits into a wider set of approaches to addressing loneliness. It can help organizations to understand the unique contribution they make to the work, and to identify the kinds of organizations they might link with to help strengthen the overall community response.

**Researchers.** For researchers, our framework can help to differentiate the range of approaches taken to address loneliness, and to identify how these can interact with others. Initially, the framework was developed to address a concern that research was making unfair comparisons – “apples and oranges” – trading off social prescribing schemes against activity groups, for example. The framework seeks to demonstrate, instead, how these types of approach can work together to address people’s loneliness. The framework sets out the broad categories of approaches, and the most common types of approach that sit underneath them.

## *The different parts of the framework*

Our publication examined the specific interventions, activities and services that collectively deliver the approach we recommend.

**Direct solutions.** These are the groups and activities that are most readily recognized as loneliness interventions, and that have been subject to most scrutiny in the literature on the subject. Direct solutions reduce loneliness by doing one or more of the following:

- Supporting people to maintain and improve their existing relationships
- Helping people to make new connections
- Enabling people to change their thinking about their social connections

Most loneliness interventions support people to develop new relationships through bringing people together in groups or one-to-one scenarios. However, work to support people with their existing relationships, either by enabling them to stay in touch or by helping them to improve the quality of these relationships, is also vital. Work to support people with the psychological aspects of loneliness is also increasingly recognized as a valuable approach in its own right. Communities need to offer a range of direct solutions so that people can find a solution that fits their particular circumstances and gives them opportunities to connect with people in ways that work for them.

**Connector services.** Connector services are needed to provide the loneliest individuals with the support they need so they can access and engage with the direct solutions available in communities. Connector services are those which:

- Reach lonely individuals
- Understand the nature of an individual's loneliness so that a personalized response can be offered
- Support lonely individuals to access appropriate services, helping them overcome practical and emotional barriers

These are the first steps that need to be taken to reduce an individual's loneliness and provide a way into the more commonly recognized interventions like social groups and befriending schemes.

**Gateway infrastructure.** Gateway infrastructure helps people to connect, and is vital for an effective community response to loneliness. Where this kind of infrastructure is unavailable, inappropriate or inaccessible, it renders service delivery difficult and makes it hard for people to connect. This infrastructure includes:

- Transport
- Digital technology
- The built environment

**System-level approaches.** System-level approaches create the environment in communities which enables loneliness to be addressed. They are not interventions, but rather ways in which local authorities and other institutions can encourage and support communities to develop approaches, groups and activities. These approaches underpin community responses. They have a dual effect – they enable the creation of both the social activities and groups that support thriving social connections, and the conditions in which loneliness is less likely to increase. For example, they can encourage participation and volunteering, which enable people to stay connected, and they can challenge the ageist attitudes that can leave both younger and older people feeling marginalized.

In the same way that good infrastructure is necessary to allow persons to connect with each other and with groups, system-level approaches are necessary to support communities to develop and sustain groups and activities where people can connect. They include:

- Neighborhood (place-based) approaches
- Asset-based community development (ABCD)
- Age-friendly communities
- Volunteering

## Cross-cutting themes

Tackling loneliness requires an inclusive approach that is accessible to all. As well as ensuring that services and activities are in place across each of the categories in the framework, specialist or adapted provision may also be necessary. The following cross-cutting themes need to be considered.

**Urban vs rural communities.** The approaches taken to loneliness are likely to look different in different communities. What is possible and desirable in urban communities may not work in rural settings, and vice versa. We highlight approaches taken across a range of different geographies, recognizing that they should be tailored to the communities which they target. Bus Buddies, for example, is one of a variety of services provided by Pembrokeshire Association of Community Transport Organizations, a group that brings together the county's very small number of rural community transport operators. It gives assistance and companionship to persons who need additional support in order to use community or public transportation.

**Action in the workplace.** Whether in the statutory, not-for-profit or private sector, organizations have a critical role to play in addressing loneliness, not just in their work as service providers and holders of community assets, but also as employers. In our publication, we highlighted approaches being taken in the workplace to address loneliness. For example, The Banks Group, a surface coal mining, property, and renewable energy company, implemented a "Managing Mental Wellbeing" approach to address mental health issues in the workplace, which are frequently caused or exacerbated by the loneliness and isolation that their miners experience while working alone in a truck all day.

**Intergenerational approaches.** Loneliness does not discriminate, and people can experience it at any age. Yet, responses to loneliness have tended to be delineated by age, particularly in the literature, where there is significant work on loneliness among older adults, but more recently, a strong emphasis on the need to better understand what works in addressing youth loneliness as well. However, in practice, many community initiatives take an all-ages or intergenerational approach to addressing loneliness, bringing together people across the generations, and enabling them to find peers in whatever way makes sense to them.

Often intergenerational initiatives are narrowly construed as being about bringing together children or young people with older adults (as in the initiatives to bring toddlers into care homes). However, the term encompasses a wide range of approaches which recognize that people of different ages may, together, find common cause and companionship. As such, it applies to many of the initiatives described in our publication.



## *Working with marginalized people*

Our publication also showcased approaches among communities that are often poorly served by mainstream services, and who may want or need specialist provision. These include:

- Black, Asian and minority ethnic (BAME) people
- Lesbian, gay, bisexual and trans+ (LGBT+) people
- Disabled people and people with long-term conditions
- Carers
- People living in residential care settings

**Black, Asian and minority ethnic older people.** Research demonstrates that loneliness is significantly higher among some, but not all, older people from minority ethnic communities, and that key risk factors for loneliness are more prevalent among older people from BAME backgrounds, who make up a growing proportion of the older population (Victor et al., 2012).

However, much less is known about what works in addressing loneliness in these communities. Language and cultural requirements sometimes mean community specific interventions are needed, and this may be particularly so among people with dementia, as it is often accompanied by a loss of ability to use second languages. Creating opportunities for cross-cultural interaction is also vital.

**Lesbian, gay, bisexual and trans+ people.** Similarly, research suggests that older LGBT+ people are particularly vulnerable to loneliness and social isolation because they are more likely to be single, live alone, and have lower levels of contact with relatives. There is also evidence that this group experiences problems in accessing mainstream provision, and lacks confidence that these services will meet their needs (Guasp, 2011). As such, there is a case both for the development of specialist support for older LGBT+ people to enable them to connect to others with whom they feel comfortable, and for action to support LGBT+ inclusion in mainstream services for older adults.

**Disabled people, and people with long-term conditions.** Disabled people and people who live with long-term conditions are at significant additional risk of experiencing chronic loneliness (Emerson et al., 2021). These groups can face particular challenges in accessing support for loneliness, in some cases, due to inaccessible venues and lack of appropriate transport, or to a failure to adapt the provision itself, for example, for people

who have sensory or cognitive impairment, or dementia. While action to improve the accessibility and inclusiveness of mainstream provision is important, there is also a case for specialist provision for disabled people and people with long-term conditions, including, but not limited to, the provision of opportunities for peer support.

**Carers.** Carers face particular barriers to connection. While practical issues – including a lack of respite care – often limit carers’ ability to connect, they can also feel distanced from the wider community due to their unique circumstances, and sometimes, the stigma surrounding their loved ones’ condition. They may also experience deterioration in the quality of their relationship with the person they care for. Carers need a range of support in addressing their loneliness, including practical support to connect with others; they often find it helpful to link with other carers for peer support, but also need support with maintaining existing relationships.

Some studies among carers of people with dementia have demonstrated that providing online support can be an effective way of helping them to stay connected. However, these links need to be complemented with other forms of connection (Davies et al., 2019; Hopwood et al., 2018).

**Older people in care settings.** There is a growing understanding that communal living is not an effective antidote to loneliness, and that, in fact, older people in residential care demonstrate worrying levels of loneliness and isolation (Victor, 2012). In recent years, there has been a concerted effort among many care providers to increase levels of connection, both between residents within care settings, and with the wider community.

Although the literature on how best to address loneliness and isolation in care settings is not well developed, there are some initiatives which have been evaluated and seem to demonstrate beneficial effects. These include:

- Introducing companion animals as an alleviation to loneliness in themselves, and as a means to foster and catalyze social connections between residents and others
- Linking care residents and the wider community – often on an intergenerational basis, for example, linking care homes with schools
- Creating social environments in homes, for example, arranging chairs in smaller groups, and even creating spaces that look like pubs and cafés

However, research in extra-care housing units has demonstrated the potential limitations of new connections between residents of communal living schemes, showing that the relationships which were most meaningful to the older people in these settings remained those they had developed in their previous lives (Burholt et al., 2013).

**Beyond local.** It is important to note that for marginalized communities, the neighborhood may not be an appropriate locus for connection. People may feel alienated from their neighbors, or there may simply not be enough peers to bring together a group within a locality. It is therefore important to make provision for communities of interest and identity to come together in ways that are meaningful to them. Where communities of interest and identity are geographically dispersed, and where people have faced barriers to meeting face to face, virtual forms of connection have often been a solution, although only for those who have access to, and confidence in using, digital technology. Examples include online forums and peer support groups for people with long-term conditions, and chat rooms and matching sites, for example, for people from certain LGBT+ communities. During COVID-19, these communities of interest have, in many cases, strengthened and grown, acting as a lifeline for many people during isolation. Many previously geographically-based groups have benefited from being able to extend their reach.

## Loneliness beyond COVID-19

As the most severe phase of restrictions eased in the spring of 2021, we started work on our report, *Loneliness beyond Covid-19* (The Campaign to End Loneliness, 2021), which was published in July the same year. The report is the biggest ever review of the impact of COVID-19 on loneliness in the UK, and discusses what can be expected in the future. We found that although restrictions on social contact during lockdown were universal, people had very different experiences of loneliness.

COVID-19 exacerbated existing inequalities, meaning that groups already at risk of loneliness – such as those who were poorer, in worse health or from ethnic minorities or LGBTQ+ communities – were at greater risk during the pandemic. We also saw that if you were already lonely before the pandemic, you were likely to become even more lonely.

The report found that organizations responsible for addressing loneliness experienced more demand for their services because:

- The coordinated response to loneliness during the pandemic identified many people who were already lonely, but not previously known to services
- The impact of COVID-19 meant that more people were likely to be at risk of chronic loneliness, perhaps because they had lost their job or been ill
- People who were already lonely experienced deep isolation, and many experienced changes in their circumstances as a result of the pandemic, making them even more lonely.

COVID-19 has opened everyone's eyes to loneliness; a large majority of people agreed that loneliness would be a serious issue even beyond the pandemic, according to multiple polls undertaken by various institutions, including the UK government's Office of National Statistics.

More of us have been touched by loneliness personally, and this has opened up conversations about this serious issue. If we pay deliberate attention to loneliness as we try to "build back better," we can support those who are already lonely, and pursue a truly connected recovery. We hope that the research we have carried out will help people in the UK and around the world to better understand loneliness and what can be done about it.

Indeed, we are part of a growing movement of organizations working to tackle loneliness. We are a founding member of the Global Initiative on Loneliness and Connection, which was launched in 2021. People and organizations around the world are welcome to join the movement, and we invite them to get in touch with us.

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# Living with the Times: addressing the mental health and well-being needs of older adults during the COVID-19 pandemic

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The COVID-19 public health emergency has disproportionately affected older adults, not only in their physical health, but also in their mental health and well-being.

A higher transmission rate and more severe outcomes of COVID-19 among older adults, the isolation measures that were required to contain the spread of the illness, and the impact of the pandemic on the broader social fabric and institutional supports of our communities, had a major impact on the well-being of older adults. This impact was even greater in communities affected by humanitarian emergencies, where the pandemic and its associated restrictions added to negative outcomes, exacerbating and complicating existing needs amongst emergency-affected populations whilst reducing access to resources.

In addition, there are few tailored Mental Health and Psychosocial Support (MHPSS) resources and service providers supporting the older adults' population group. There is also discrimination against older adult populations, whose needs are often forgotten in humanitarian settings.

In this context, it was important for the MHPSS community and experts in older adults to come together to develop resources to contribute to their well-being during the public emergency response.

## Living with the Times

“Living with the Times” (Inter-Agency Standing Committee, 2021) is a unique resource created with and for older adults affected by the COVID-19 pandemic (see link in References).

In the early response to the pandemic, an eclectic working group of the Inter-Agency Standing Committee (IASC) Reference Group on Mental Health and Psychosocial Support (MHPSS) in Emergency Settings – co-chaired by the World Health Organisation and the IFRC Centre for Psychosocial Support (see IASC MHPSS Reference Group, n.d.) – developed important guidance for the integration of the needs of older adults in the global public health response (Inter-Agency Standing Committee, 2020b, 2020a).

Following these efforts, the need for practical tools to be used in addressing the well-being needs of older adults led the working group to develop a more dynamic tool directed, not to the responding agencies, but to affected older adults themselves: a toolkit for older adults to support themselves in maintaining good mental health and well-being during the COVID-19 pandemic. The working group members were also cognisant of the fact that older adults are usually not online or following social media platforms, that there are higher levels of illiteracy among older adults in lower income countries, that they listen to messages coming from “respected elders” or authorities such as medical, social welfare staff and religious leaders, and respond well to both oral and visual communication methods. This information was gained through a scoping exercise and discussions with key groups such as the HelpAge network and Alzheimer’s Disease International, and organisations such as the International Organisation for Migration, the World Health Organisation, and the Red Cross and Red Crescent Movement that promote healthy ageing programs.

The toolkit contains five posters that use visual story-telling to convey key messages for older adults on how to maintain well-being during the COVID-19 pandemic while supporting those around them. Specifically, the posters address the following topics:

- How can I stay healthy?
- What can I do to improve my mood?
- How can I feel connected to my family and community?

- Where can I get help if I need it?
- How can I cope with grief and loss?

Thanks to their unique design, the posters require minimal reading skills, are culturally diverse, and aim to engage older adults in conversations and activities, rather than simply share information with them.

**Figure 1**

Five “Living with the Times” posters



Note. By the IASC MHPSS RG in Emergency Settings, 2021. (<https://interagencystandingcommittee.org/iasc-reference-group-mental-health-and-psychosocial-support-emergency-settings/living-times-mental-health-and-psychosocial-support-toolkit-older-adults-during-covid-19-pandemic>). CC BY-NC-SA 3.0 IGO.

The toolkit also includes facilitators' notes with instructions on how to use these posters to guide conversations in community senior groups and similar settings. These notes include instructions on how to prepare the sessions, both for individual and group support; scripts for leading conversations; frequently asked questions and answers; and additional



resources and further readings. The posters and the facilitator notes are designed in such a way that each can be used alone or in combination.

The final, and ongoing, part of the process, was to facilitate the toolkit's translation into six more languages, and to then coordinate the wonderful support provided by individuals, organisations and institutions globally to produce more translations. As of May 2022, “Living with the Times” has been translated into 23 languages and adapted into three accessible formats.

## Co-creation process

It's important to highlight the process by which the toolkit was created. The working group creating “Living with the Times” wanted to develop a tool that would be broadly used in diverse contexts (humanitarian, urban, rural, institutional, community, etc.), and that would have a positive reception by older adults themselves. The way to achieve this was to create “Living with the Times” together with those who would eventually use it, in a co-creation process.

A total of 199 older adults aged between 60 and 90 years, from 51 countries, helped develop and test the toolkit, including from different income groups and contexts, as well as humanitarian settings. The tool was then field-tested in different countries, income groups and contexts, including humanitarian settings, by the network of country-level MHPSS Technical Working Groups, which are the humanitarian coordination structures at country level that ensure the coordinated and collaborative humanitarian response of agencies and organisations providing MHPSS implementation.

At the beginning of the process, a list of approximately 30 recommendations to improve the well-being of older adults was identified by the experts involved in the project. Once these recommendations were identified, the working group initiated a collaboration with The Ink Link, an NGO specializing in transmitting information more efficiently through adapted visuals.

The initial idea was to illustrate each of the 30 recommendations, but the working group agreed that this might not be the optimal solution for older adults, who might be experiencing memory problems.

The Ink Link works on three components to ensure a good transmission of messages:

1. Acceptability of the message: The transtheoretical model of change suggests that, in order to induce a change of practice in an individual, it is necessary to go through different phases or “steps.” Asking a person to move too fast (from not being aware of

a fact, through awareness, to immediately making a change) may create the opposite effect to that intended.

2. Understandability of the message: The way the information is delivered needs to be culturally adapted, and adjusted to the education level of the recipient. Several representations (e.g., tables, changes of scale, representations of abstract concepts) need specific attention as they are not universally understandable.
3. Memorisation process: Several factors can increase the memorisation of the information.

In the creation of “Living with the Times,” these three components were addressed through different methods:

### **1. Acceptability**

The transtheoretical model of change proposes that individuals need to go through different stages to make a change in habits: from a pre-contemplation stage (i.e., the person never heard of or thought about making that change), to a contemplation stage (i.e., being aware of the possibility of change), to a preparation phase (i.e., considering making a change and looking for information about it), to an action phase (i.e., putting a new practice in place).

In “Living with the Times,” it was proposed to combine the 30 recommendations originally identified by the group into five large posters that older adults could interact with. These posters contain several small scenes in which older adults engage in actions related to the well-being recommendations. Some scenes might not be directly applicable to a particular person; for example, some people may never have practiced handcrafts, and if they were asked directly to do them, they may be reluctant (pre-contemplation phase). Instead, they could find in the particular poster they are looking at other activities that they would agree to engage with, for example, gardening (preparation or action phase). Looking at all the information in the poster can help a person identify and choose activities to engage with readily, as well as suggest other activities to consider, so they transition from a pre-contemplation phase to a contemplation phase that allows for possible changes later.

### **2. Understandability**

To develop a visual tool that could be presented for use worldwide, to an audience with very different backgrounds, cultural practices, and levels of education, was a great challenge. Some graphic styles may be more or less easy to understand and appreciate than others. The first step was to test different graphic styles with older adults worldwide. A questionnaire was prepared, showing six sets of illustrations and asking about the person’s preference. For each of the six sets, one component was evaluated: a more or less realistic style, the capacity to identify with a character that looked more or less like

the person, the colours used, and so on. A total of 199 older adults aged between 60 and 90 years, from 51 countries, participated in the test, allowing the design team to choose an artist who would be appreciated by a large audience.

Afterwards, when finalising the design of the posters, several instructions were given to the artist in order to facilitate understanding of potentially complex visual aspects by a more or less literate audience (e.g., to avoid perspective, and to put all scenes on a similar or even level).

### 3. Memorisation

Given the natural capacity of the human brain to filter the large quantity of images it commonly receives, selecting only the most relevant information for processing and memorising, it was important to put in place specific processes that would facilitate long-term memorisation of the content. The facilitator notes and instructions integrated these processes to facilitate memorisation, and included:

- Asking the older adult the question that is the theme of each poster; for example, “How could you stay healthy?”
- Allowing the older adult to think about the question and express their ideas out loud, so there is an activation of the attention of the person to the topic.
- After ideas have been shared, showing the poster which contains a large set of ideas related to the same question, and asking the older adult to look for other ideas in the poster, and to describe them. In this way, the person is engaging in active reading which allows an interesting analysis of the content (e.g., “Does that apply to me?” and “What are they doing there? Could I do it too?”).
- Encouraging the older adult to communicate what interests them with the caregiver, which provides additional memorisation support by verbalizing their ideas.
- Summarising the ideas formulated by the older adults, which will contribute to the processing and memorisation.
- Supporting the person in thinking about ways to put the ideas gathered into action, to help initiate the process of changing habits and routines and integrating new, well-being-oriented activities into their lives.

## Conclusion

With the development of this tool, the IASC Reference Group for MHPSS in Emergency Settings and the experts and agencies who contributed to the process, supported addressing the well-being concerns of older adults impacted by COVID-19. “Living with the Times” has had a very positive reception, and continues to be translated and used in COVID-19 responses in multiple countries across the world.

This development points to several key conclusions:

- In responding to emergencies, including public health emergencies, it is essential to prioritise older adults as much as other age groups, integrating in the responses the necessary adaptations to ensure they are not left behind.
- Generating tools and resources that specifically address the mental health and well-being concerns that result from emergencies is an indispensable part of this age-inclusive emergency response.
- In developing these tools, co-creative and inclusive procedures, which put at the centre of their designs the inputs and ideas of older adults, must be prioritised.

### Figure 2

*Using “Living with the Times” in the field in Syria*



*Note.* By the World Health Organisation.

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## ASEM

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ASEM addresses political, economic, financial, social, cultural and educational issues of common interest in a spirit of mutual respect and equal partnership. Its foremost event, the ASEM Summit, is a biennial meeting between the Heads of State and Government, the President of the European Council, the President of the European Commission, and the Secretary-General of ASEAN. In addition, ASEM Ministers & Senior Officials also meet in their respective sectoral dialogues.

The initial ASEM Partnership in 1996 consisted of 15 EU Member States, 7 ASEAN Member States, China, Japan, Korea and the European Commission. Today, ASEM comprises 53 Partners: 30 European and 21 Asian countries, the European Union and the ASEAN Secretariat.

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For more information, visit the AGAC website ([www.asemgac.org](http://www.asemgac.org)).

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