



care  
inspectorate



# Meaningful Connection

Literature Review  
Anne's Law Project



HAPPY TO TRANSLATE

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## Acknowledgements

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## Executive summary

A review of relevant literature was carried out on the subject of meaningful connection for people who experience care in care homes. The key findings were as follows:

- Meaningful connection is profoundly important to people's emotional, mental and physical wellbeing and their quality of life. A lack of connection can lead to social isolation and loneliness, which can have a detrimental effect on people's health and wellbeing.
- The Covid-19 pandemic had a devastating effect on people's experiences of connection. This impacted people experiencing care, their families and friends, and care home staff.
- People experiencing care have a wide range of possible relationships. This includes families and friends, peers, staff, and the wider community, all of which have the potential to enrich everyday life and support personhood.
- Family carers have an essential part to play as partners in care, fulfilling a variety of roles which support people's wellbeing, and going far beyond "just being a visitor".
- Everyone has their own individual connection needs and wishes. Holistic, person-centred assessment and planning which values personhood is of paramount importance. This should consider how the use of technology can enhance connection when used in a meaningful and thoughtful way.
- There are barriers and challenges to meaningful connection. Not all people experiencing care have the same opportunities due to a variety of reasons; for instance, sensory or cognitive impairment, or the effects of chronic life-limiting conditions. Positive strategies to overcome these can be developed to support everyone to connect in ways that are right for them.

## Introduction and background

The Anne's Law Project aims to uphold the rights of people who live in adult and older people's care homes, with a particular focus on promoting meaningful social connection and community involvement. To enable the project to provide evidence-based guidance and support, a review of published literature on the subject of meaningful social connection for people who live in care homes was completed. It was envisaged this would enable a greater breadth and depth of understanding of issues relevant to the project and provide a clear narrative for future work.

On 31 March 2022, there were an estimated 33,352 people aged 18 and over living in 1,051 registered care homes in Scotland. People living in care homes for older people accounted for 92% of the total number (Public Health Scotland, 2022).

Meaningful contact with others is fundamental to people's health and wellbeing and is integral to their human right to a private and family life. However, the Covid-19 global pandemic meant meaningful connection for people living in care homes was placed under intense pressure, primarily due to visiting restrictions and distancing policies which aimed to reduce the risk of transmission. The difficulties of balancing people's social needs and rights to a private and family life against minimising the risks of infection were keenly felt, and the people who were most affected – people living in care homes and their loved ones – lacked a voice in decision-making (Scottish Human Rights Commission, 2021).

It is widely acknowledged that people living in care homes have been disproportionately affected by Covid-19 (Bethell et al., 2021). The social isolation experienced by people living in care homes during the pandemic has had a detrimental effect on their health and wellbeing (Sweeney et al., 2022). The steps taken to reduce the risk of infection resulted in other health risks, with a "devastating impact" on social connection for people experiencing care (Bethell et al., 2021). Public health restrictions meant communal areas were closed off and people living in care homes were confined to their rooms to self-isolate. The visiting ban in the early stages of the pandemic meant social contact was not feasible (Noten et al., 2022). Frequent changes in guidance led to confusion for many, with evidence indicating that guidance was not always implemented "consistently, equitably and proportionately" across the care home sector (Palattiyil et al., 2021).

Social isolation and loneliness are harmful, as they can reduce older people's life expectancy and damage their health and wellbeing, including their quality of life (Annear et al., 2017; Lem et al., 2021; WHO, 2021). Until recently, social isolation and loneliness among older people has been considered a neglected social determinant of health. However, increased recent recognition has brought this to the fore, with greater public health and public policy focus. The Covid-19 pandemic and

the effects of physical distancing measures have also highlighted how stark social isolation and loneliness have become, which has been the impetus for further action regionally, nationally, and globally (WHO, 2021).

Following campaigning by relatives, in September 2021, the Scottish Government announced a commitment to introducing “Anne’s Law”, intended to strengthen the rights of people living in care homes to have direct contact with those who are important to them, even in times of outbreak (Scottish Government, 2021). On 31 March 2022, two new Health and Social Care Standards were introduced, reinforcing the rights of people living in care homes to see and get support from the people who are important to them even in outbreak situations (Scottish Government, 2022).

This review will provide an in-depth narrative on the effects of social isolation and the importance of connection for people living in care homes and discuss the key themes emerging.

## Note on terminology

There is no single agreed term to describe the role of families, friends, and those important to people experiencing care, and various terminologies are used throughout the literature.

For the purposes of this literature review, we have used the term “family carers” to refer to immediate and extended family, friends and other close contacts who play ongoing roles in the lives of people who live in care homes.

The term “people experiencing care” has been used throughout this review to refer to people who live in adult and older people’s care homes.

## Methodology

The below details the process by which the narrative literature review was completed, including search strategy, limitations, and exclusion criteria.

## Search Strategy

An online search strategy was completed through OpenAthens using the full collection within The Knowledge Network. In addition, a further search was completed using academic search engines: CINAHL and the Cochrane Library. Table 1 sets out the search terms used to elicit appropriate resource returns.

Mode (any field)	People (subject)	Setting (subject)
Social connection Meaningful connection Social contact Meaningful contact Visiting Visitation Visits Engagement Meaningful engagement Social engagement Social support Connection	People experiencing care or variation therein Residents Service users Patients Family carers Families Loved ones Relatives Unpaid carers Visitors Friends Family contacts Family Adults Older people Aged  NOT (subject) Child Adolescent Babies Youth	Care homes Older people's facilities Older person facility Residential homes Residential care Nursing homes Long term care Old people's homes Elderly care homes Care facilities  NOT (Any field) (India OR China OR Korea* OR Japan OR Taiwan OR South Korea OR Hong Kong)

**Table 1** – Search terms

All plural terms have been suffixed with an asterisk to provide search results containing variations of a root word.

To focus this to appropriate sources, these limitations and exclusion criteria were added.

Limitations	Exclusions
<ul style="list-style-type: none"> <li>• Period: 2017-2022</li> <li>• Full text articles</li> <li>• Peer review articles</li> <li>• UK and other countries with similar demographics</li> </ul>	<ul style="list-style-type: none"> <li>• Non-residential care settings</li> <li>• Not related to people experiencing care</li> <li>• Not related to relatives/carers</li> <li>• Articles not in English</li> <li>• Opinion papers</li> </ul>

As the focus of the paper was on meaningful connection and to ensure a breadth of experiences were captured, not entirely focused on the effects of the Covid-19 pandemic, the search was limited to literature published between 2017 and 2022. As this covered the period both before and during the Covid-19 pandemic, it has however, allowed for a richer narrative to be developed.

A total of 520 articles were returned.

Abstract analysis was completed and allowed for a focus on resource content. From this, a total of 96 resources were deemed appropriate for inclusion. As the literature review purpose is to provide a conceptual understanding of the subject matter, no limitations for primary or secondary sources were set. However, secondary resources were kept within the limits of systematic reviews and meta-analyses, where clear literature search strategies could be demonstrated. Following full analysis of the resources accessed, a further 50 were deemed as inappropriate in informing the evidence-base due to not clearly meeting the inclusion criteria, as were some studies focusing on evaluating individual assessments, or tools.

We did not use a specific tool to assess the quality of the articles due to the variability in the studies included. Articles were deemed suitable for inclusion if they presented clear methodology and were evaluated as high quality following discussion within the research team.

To ensure the literature captured all relevant papers, references were hand searched to gather further relevant sources. This resulted in six further articles being included.

The resulting 52 review articles were the basis for the literature review, with four prominent themes and 15 subthemes emerging, as discussed below (see Table 2).

Overarching Themes	Subthemes
The health and wellbeing outcomes associated with social connection.	<ul style="list-style-type: none"> <li>• Social isolation and loneliness in care homes</li> <li>• Emotional wellbeing</li> <li>• Mental wellbeing</li> <li>• Physical wellbeing</li> <li>• Quality of life and thriving</li> <li>• Strategies and recommendations for improving connection</li> </ul>
The types of relationships experienced by people who live in care homes and why they matter.	<ul style="list-style-type: none"> <li>• Relationships with peers</li> <li>• Relationships with staff</li> <li>• Relationships with the wider community</li> </ul>
The roles and involvement of family carers and why they matter.	<ul style="list-style-type: none"> <li>• Social and emotional support</li> <li>• Advocacy and monitoring</li> <li>• Providing direct care</li> <li>• Barriers and enablers</li> </ul>
The role of technology in facilitating connection.	<ul style="list-style-type: none"> <li>• Communication technology</li> <li>• Other forms of technology</li> </ul>

**Table 2** – Themes from literature

## Health and wellbeing outcomes associated with social connection

Meaningful engagement, which is essentially participating in something that brings personal enjoyment and value, is considered essential to ensuring a good quality of life and influences individual wellbeing (Ciofi et al., 2022). Participating in a meaningful activity, such as a simple task or experience which is valued, has also been shown to increase life expectancy (Pastor-Barriuso et al., 2020). Cultivating social relationships is central to promoting wellbeing for people living in care homes (Kang et al., 2020).

Social relationships allow people to feel valued as individuals and empowered as partners in care. The variety of relationships people have, and the people they engage with, all have the potential to bring something and contribute to the relationship in a unique way, which can affect people's lives positively or negatively. With this in mind, human relationships which bring meaningful social connection are a powerful vehicle to improve psychosocial wellbeing (Kang et al., 2020). Due to Covid-19 restrictions, people living in care homes were unable to access other means of psychosocial support which also led to adverse effects on social functioning and mental health (Sweeney et al., 2022).

This theme will review how social connection affects people's emotional, mental, and physical health and wellbeing, and discuss the outcomes people may experience when they are unable to connect with what is important to them. Due to how complex this subject is and how interlinked each aspect of health is, there may be some overlap, although we have tried to address each aspect separately.

## Social isolation and loneliness in care homes

Loneliness can be defined as a painful subjective feeling, resulting from a state of being alone, separated or apart from others when there is disparity between the desired and actual social contact or connections (Gardiner et al., 2020; WHO, 2021). Feelings of loneliness can include fear, sadness, and powerlessness. However, the diverse nature of loneliness is apparent and described as an individual experience (Noten et al., 2022).

Social isolation can be described as social disconnectedness (Budak et al., 2021). The most prevalent cause of loneliness during the Covid-19 restrictions was reported as missing contact with other people and reduced activity. Not all people who are socially isolated are lonely and the impact on individuals is unique, with outcomes determined by individual coping strategies, social needs, and personal character



traits. People who described themselves as 'a social person' found the restrictions more difficult (Noten et al., 2022). The implementation of care home policies and procedures that focused on the collective safety of people relating to infection prevention and control, coupled with staffing pressures, meant there was increasing difficulty for staff to provide person-centred care. This also led to loneliness due to loss of autonomy and self-determination (Noten et al., 2022).

Prevalence of loneliness among older people living in care homes was the focus of a systematic review (Gardiner et al., 2020) which included findings from 13 articles which involved 5115 participants. The large cohort emphasises how stark the prevalence is, as both moderate and severe loneliness were experienced among care home residents. The meta-analysis found 61% of older people living in care homes may be moderately lonely and around 35% may be severely lonely. Although differences in the studies means that consideration should be taken when drawing conclusions; the results nevertheless emphasise there are significant concerns among older people living in care homes and their experiences of loneliness. These results are consistent with the findings of a study by Budak et al. (2021) who also reported that people living in care homes experienced moderate to severe levels of loneliness.

Moving to a care home from a community setting means the environment and social structures change. This can make it more difficult for people living in care homes to extrapolate meaning from those around them as they do not have established support networks (Annear et al., 2017). High rates of loneliness may differ with the perception that people living in care homes have plenty of people around them. However, reduced social networks on entering a care home, such as the loss of a spouse may mean that high levels of loneliness are already experienced on admission to a care home (Gardiner et al., 2020).

Social isolation and loneliness can be impacted by progressive age-related conditions and sensory impairment (Annear et al., 2017). Factors that contributed to loneliness in older adults were poor health (including dementia symptoms), loss of independence and autonomy, lack of privacy, loss of friends, and lack of social interaction (Lapane et al., 2022). Several common themes emerged from the studies, which highlighted how people living in care homes coped with loneliness. While individual resilience was an important factor, social support and engagement in activities helped to reduce negative outcomes. Other ways of coping included acceptance of their current life situation, fostering meaningful relationships, help from staff, family support and people's own religiosity (Lapane et al., 2022).

## Emotional wellbeing

The separation from loved ones during the first wave of Covid-19 restrictions was described by family carers as emotionally painful. This was exacerbated by the difficulties surrounding modes of communication for keeping in touch (Avidor & Ayalon, 2022). The need for social connection is an individual experience and negative emotions varied from person to person (Noten et al., 2022). Physical separation evoked feelings of sadness, frustration, anger, and loneliness for family carers, expressing they perceived their loved ones as feeling lonely, depressed, scared. Some felt people living in care homes lacked understanding about the restrictions, which added to the perceived distress (Hovey & Shropshire, 2021; Kusmaul et al., 2022). For people living with a sensory impairment, this added to the distress of trying to stay in touch (Hovey & Shropshire, 2021). Family carers felt disconnected from those living in care homes (Kusmaul et al., 2022) while others felt experiences of fear and loss took its 'emotional toll' (Palattiyil et al., 2020).

Negative experiences were not only related to expressed loss and grief at being separated. However, many spoke about fears regarding the decline in their loved one's health and wellbeing. Fears about not getting back the lost time, or 'remaining good days' caused increasing distress and a fear that time was running out (Palattiyil et al., 2020). All family carers in another study felt that for those living with dementia, their cognitive symptoms had declined. They conveyed feelings that their loved ones had experienced irreparable harm from prolonged separation. They recognised the need to protect people from a 'deadly disease' was important, however, they voiced that long-term separation from family carers cannot be condoned (Kusmaul et al., 2022). Additional fears surrounded information about the Covid-19 virus itself and the possibility of passing it on. At the start of the pandemic there was little information available (Noten et al., 2022).

Prior to the pandemic, a Canadian study looked at the experiences of spouses following involuntary separation related to their spouse moving into long-term care and they relinquished their usual care giving role. It was described as an overwhelming burden marked by ongoing losses; the move to a care home was made more bearable when social connection was available and when spouses were able to continue their relationship together, albeit living separately (Glasier & Arbeau, 2019). Although experiences are perceived individually, these experiences add context to the added impact the Covid-19 pandemic has had especially for those transitioning to long term care during periods of restrictions. The added restrictions and limitations for meaningful connection during the pandemic would have exacerbated the experience of loss. The activities and contact that improved family carers' experiences could not have happened.

Family carers were also worried about the needs of relatives being unmet (Palattiyil et al., 2020). Family carers were so concerned about their relatives' wellbeing that a study by Pirhonen et al. (2022) indicated that 46% of the participants reported the concerns had adversely affected their own wellbeing. However, it is worth considering the different factors that may have been present for each individual. While we acknowledge the impact, outcomes can be dependent on a variety of reasons. Increased concern may also be related to the confidence that family carers had in the care provided or with the transparency of the service. Some family carers had reported changes in their loved one's wellbeing which had also increased their concern (Pirhonen et al., 2022).

During Covid-19 restrictions, some family carers reported the usual care and support people experiencing care received was reduced or neglected. This added to family carers' shock and distress. While people acknowledged there would be a natural physical decline due to people's age or pre-existing conditions, family carers expressed concern about an acute decline in their loved ones' physical health, including a variety of factors from weight loss, changes in mobility, pressure ulcers, dehydration, and unkempt appearance (Sweeney et al., 2022). Similarly, family carers reported that the visiting restrictions had a profound negative physical and/or cognitive impact on their relative. Although families understood that those with dementia would have a natural decline, the families felt this was accelerated. People experiencing care also lost weight due to decreased appetite or the lack of family support or presence to assist with meals. Many also experienced physical decline due to mobility issues resulting from isolation in rooms (Kusmaul et al., 2022).

Lack of communication led to family carers feeling excluded and concerned, which contributed to their distress (Giebel et al., 2022b). Care home staff and family carers noted deteriorations in people experiencing care, which affected both their physical and mental wellbeing. Some people were clearly upset due to not being able to see their family members, although some family carers reported visits were arranged when there were difficulties with their loved ones, such as stress and distress, or loss of appetite which led to physical deteriorations. Family carers noted these changes may have been due to the fact the person was living with dementia and may have occurred regardless of the restrictions. However, family carers reported that certain presentations of their dementia were now considered more difficult to manage due to the restrictions (Giebel et al., 2022b).

When looking to understand family carers' lived experiences in relation to trauma, four trauma related themes emerged in one piece of research (Chu et al., 2022a). These were trauma from prolonged separation from loved ones, trauma from uncompassionate interactions from staff and admin, trauma from the inability to provide care to loved ones, and trauma from experiencing prolonged powerlessness and helplessness. The profound results from this study encapsulate family carers' experiences as a collective trauma that deeply impacted their relationships with their

loved ones as well as their perceptions of the long-term care system. The researchers discussed the effects that prolonged stress can have on people's health and wellbeing such as noticeable changes in their body, actions and thinking (Chu et al., 2022a).

'Skin hunger' was an expression reported in Noten et al., (2022), which could be explained as the need for touch. Several reasons for people's experiences of loneliness were found, most commonly due to the lack of contact with their relatives and other people. They missed physical contact with people and hugs. Some made comparisons to feeling like they were in prison or remembering World War II. People reported there was not much to look forward to each day when there were no visits or planned activities in the care home. In this study, family carers who were spouses experienced higher levels of loneliness compared to other relatives (Noten et al., 2022). The absence of touch was a factor that led to emotional distress for family carers (Palattiyil et al., 2020).

The lack of opportunity for people experiencing care to receive comfort, reassurance from others and touch has contributed to their general decline. It is worth noting the conflict felt by staff members during this time. Although family carers at times felt staff prioritised public health measures over personalised care, staff also recognised the detrimental effects social isolation was having on people's health and wellbeing (Sweeney et al., 2022). Staff themselves were experiencing high levels of stress, burnout and were working in unprecedented times. Staff and family carers reported the media representation of blame also added to unnecessary emotional distress (Sweeney et al., 2022).

Social connection can lead to positive outcomes for people in relation to their mood and emotions. However, for people living with dementia who were included in some of the research studies, the findings indicated it was difficult to evaluate their experiences. This was due to the variability of their condition and the associated factors that can precipitate change for people living with a cognitive impairment (Bethell et al., 2021).

How people perceive the quality of social interaction experiences can affect people's emotional state. A participant living in a care home described the only interaction she had as "fleeting daily visits from carers, cleaners or nurses, and generally infrequent visits from family members" (Annear et al., 2017). It is worth noting that this study was undertaken prior to the pandemic, but demonstrates how social interactions can be experienced. Social isolation can increase due to a progressive decline in people's functional ability and general decline in their health. Qualitative data does suggest that for many older people living in care homes, social engagement which is of poor quality and their progressively reduced ability to be able to interact with others led to an increased sense of isolation (Annear et al., 2017). This was consistent with findings by Noten et al. (2022), although there were limitations to this study as some participants did not report they experienced loneliness. This may be due to those individuals experiencing advanced dementia which meant they or their family carer could not express if this was a concern.

## Mental wellbeing

Social connection in relation to mental health outcome was the focus of a large scoping review by Bethell et al. (2021). The mental health outcomes extrapolated were depression, responsive behaviours, mood, affect and emotions, anxiety, medication use, cognitive decline, death anxiety, boredom, suicidal thoughts, psychiatric morbidity, and daily crying. Although there were methodological differences between the studies, making it more difficult to make direct associations, it does highlight how widely social connection can impact mental health. Loneliness among older adults was also noted to be associated with self-neglecting behaviours (Budak et al., 2021).

Family carers have also experienced significant mental distress. When mental health scores were reviewed as part of a study, family carers' mental health scores were significantly poorer than those of the general public. Concerningly, 76% of participants met the threshold for clinical mental distress. This affected women more notably, and partners of relatives, rather than children. Family carers who visited the care home more frequently (once or twice a week) prior to the restrictions also presented with a higher score. Symptoms included preoccupation of thoughts about their loved one's wellbeing, feeling more stressed, losing sleep, and feeling unhappy or depressed (Palattiyil et al., 2020).

A study looking at the impact of visiting restriction on family carers and people living with dementia also found family carers experienced negative outcomes. This included social isolation, strain, and reduced quality of life. When able to visit the care home, family carers noticed dementia progression, with 51% reporting an increase in dementia-associated responsive behaviours since the pandemic began. Family carers felt that if they had been able to visit and provide support, they could have supported people with managing behaviours using non-pharmacological means. They were concerned at the potential adverse effect of anti-psychotic medication that had been used for these associated behaviours (Hindmarch et al., 2021).

## Physical wellbeing

Loneliness is a major health problem for older people and is associated with a range of negative health consequences including cardiovascular disease, malnutrition, poor quality of life and mortality (Budak et al., 2021; Gardiner et al., 2020).

Perceived social isolation can trigger a physiological response in some endocrine systems, affect the immune system and increase inflammatory responses which can be predisposing factors in some chronic conditions (Pastor-Barriuso et al. 2020).

Biological factors can be triggered by loneliness and can also lead to the progression of symptoms of dementia and mild cognitive impairment (Budak et al., 2021).

As social connection is recognised as an important determinant of health and wellbeing, it can therefore promote physical health. A scoping review by Lem et al. (2021) looked at 34 studies covering a wide range of health outcomes. These included mortality, self-rated health, sleep, fatigue, nutrition, hydration, stress, frailty, and others. Findings overall supported the positive impact of social connection for physical health among people living in care homes (Lem et al., 2021). Similarly, a systematic review of 31 articles by Lapane et al. (2022) focusing not only on the health effects of loneliness and social isolation, but seeking to evaluate how this affected older adults living in care home settings, common themes emerged. In most studies, loneliness was suggesting links to depression, however suicidal ideation and frailty are also of note. They summarised that a lack of social connectedness leads to isolation and loneliness and should be considered a new 'geriatric giant' (Lapane et al., 2022).

When people experienced strong social relationships, mortality risk was noted to have halved according to a meta-analysis by Annear et al. (2017). This is consistent with findings in a 10-year cohort study involving 382 care home residents which found that those who experienced high levels of social engagement within the care home had an 18% lower 5-year mortality risk and a 3-year increase in median survival rate (Pastor-Barriuso et al., 2020).

How people experience pain was found to be linked in two studies when people felt they had reduced social relationships and increased loneliness. However, other studies found there was no association with pain, although some variations emerged in the participant demographics making it difficult to draw comparisons. Some people were living with a cognitive impairment, and it was unclear how pain was being consistently assessed, which may have influenced the results. Pain may also prevent people from engaging in social connection or activities, so it is important to be mindful when making an assessment (Bethell et al., 2021).

## Quality of life and thriving

Value placed on social relationships, taken together with engagement in something meaningful, are described as a key component for successful aging and important factors in ensuring a good quality of life. Family carers can contribute to people's quality of life as they are familiar with people's personalities, wishes and the individual support needs of their relative (Noten et al., 2022).

People living in care homes reported the main reason they engaged in activities was primarily to stay socially connected. The components of thriving can be described as

the relationship someone has with their environment, being their lived experience. When looking at the concept of thriving and how engagement with everyday activities impacted people's experiences, the most common everyday activities people valued were receiving hugs, physical touch, talking to relatives/friends, and receiving visitors. People also valued when staff took time to engage in conversations not specifically related to their care. Surprisingly, the least common was going out (Björk et al., 2017).

In a study looking at people living with dementia in a care home environment, and the opportunities they had to get outside, being able to be out in the outside world was linked to wellbeing and quality of life. Although, the right level of support to ensure the experience was beneficial to help 'negotiate connections', as not all experiences were positive (Ciofi et al., 2022).

Positive links to thriving were also noted when people were engaged in a meaningful activity, dressed nicely, and were able to spend time with someone they liked. These had the greatest impact on someone's perception of thriving. Everyday activity can support individual's personhood while engagement has association with improved quality of life and wellbeing (Björk et al., 2017).

The concept of thriving was explored by Baxter et al. (2021) who looked at seven qualitative studies. They concluded that a person-centred approach would ensure someone's 'recipe' for thriving when met by the right ingredients and the right environment. This was then determined by individual 'taste', of which the key features identified were personal attributes, relationships with others, the lived environment, and societal structures. Again, the uniqueness of the lived experience comes through, and ensuring that people's preferences are honoured in relationships and the ability to be able to go outside. Being involved in meaningful activities and feeling cared for also played an important part in people's perceptions. Contributing factors were described as "satisfying social interactions and connection with others" which included positive peer relationships (Baxter et al., 2021).

## **Strategies and recommendations for improving connection**

Lack of social connection clearly impacts people's emotional, mental, and physical health and wellbeing. The findings warrant concern, and although variations exist in experiences due to the unique nature of human beings, interventions can be implemented to address loneliness. Promoting meaningful social engagement in care homes will ultimately enhance quality of life for people experiencing care (Gardiner et al., 2020). Strategies can be implemented by people living in care homes, staff, and family carers to develop and maintain social connection (Bethell et al., 2021). The research suggests developing a tailored individualised plan could improve people's long-term survival and improve their quality of life (Pastor-Barriuso

et al., 2020). Implementing innovative interaction strategies to alleviate loneliness (Lapane et al., 2022) and creating opportunities for meaningful engagement leads to affirmation of personhood, which fosters meaning, thus addressing isolation resulting in improved quality of life (Annear et al., 2017).

The key challenge is therefore to determine ways of developing and nurturing social relationships within the care home. This should include opportunities for people to engage in everyday activities which are meaningful to them as individuals (Gardiner et al., 2020). The need for social connection is recognised as an unmet need (Annear et al., 2017). Should an outbreak of infectious disease occur and restrictions be required, strategies should be implemented to ensure physical, emotional, and social needs are met (Sweeney et al., 2022).

Pain may prevent people from engaging in social connection or activities, so it is important that people have a full holistic, multi-factorial assessment to identify any contributing factors present which may inhibit their full participation. This includes consideration of factors affecting people's mental health (Bethell et al., 2021).

Providing family carers with detailed personalised information of how their loved one is doing has the potential to alleviate some of the distress and anxiety experienced by family carers (Pirhonen et al., 2022). Involving family carers, and valuing the information they can provide, can also support the assessment process. This information can then support in the process of undertaking an individualised holistic assessment and developing a personal plan which focuses on people's choices, wishes, and defines their personhood (Noten et al., 2022).

Sharing good practice and establishing what works well, for whom, and in what circumstances can help others gain insight into how loneliness can be addressed more consistently. Successful interventions can then be shared and implemented more widely. As a large proportion of people living in care homes have a cognitive impairment, and with the increased risks of loneliness in this group, and the complexities around gathering findings, more research is needed to fully establish how dementia impacts people living in care homes in relation to loneliness (Gardiner et al., 2020).

## **The types of relationships experienced by people who live in care homes and why they matter**

Moving into a care home changes people's social networks, introducing new challenges in maintaining existing relationships, and opportunities for new relationships to form (Kang et al., 2020; Lovatt, 2021). Despite the apparently social nature of care home life, reduced contact with family, friends and the wider



community, a lack of meaningful interaction with peers, and staff who lack time for conversation can lead to feelings of isolation and loneliness (Annear et al., 2017; Gardiner et al., 2020). Research has shown the prevalence of moderate and severe loneliness among people living in care homes is high (Budak et al., 2021; Gardiner et al., 2020).

Theme 1 presents a large body of evidence to show how meaningful social relationships are important to a range of health and wellbeing outcomes. People in care homes experience a range of relationship types, both within the care home (peers, staff) and outside it (families and friends, the wider community). An understanding of why these relationships matter, and the factors that influence them, can help support better outcomes for people, and this is discussed below.

Meaningful relationships and social connections were placed under intense pressure or suspended entirely due to Covid-19 restrictions, and as a result, social needs for many went unmet (Noten et al., 2022). People were often confined to their own rooms for lengthy periods (Noten et al., 2022; Sweeney et al., 2022), physically separated from their loved ones and peers, and cared for by staff who were under severe pressure (Giebel et al., 2022a; Hanna et al., 2022). The impact on connectedness was stark, with people reporting increased loneliness, isolation, and fear, with greatly diminished opportunities to receive comfort and reassurance (Noten et al., 2022; Sweeney et al., 2022).

## Relationships with peers

Research among people living in care homes (Abbott et al., 2018; Nygaard et al., 2020; Roberts, 2018), including people with dementia, about their social relationships found that many expressed a desire for greater opportunities to socialise within the home and to form meaningful relationships and communities with their peers. Friendships were facilitated by common interests and enriched everyday life (Nygaard et al., 2020; Roberts, 2018), fostering a sense of belonging and purpose (Kang et al., 2020) and supported people to feel “at home” in their environment (Lovatt, 2021); however, research has noted that few people experiencing care described close relationships with peers. Comments included, “No friends here”, and “No-one to talk to” (Abbott et al., 2018; Roberts, 2018). Nygaard et al. (2020) found that generally, it was only by coincidence that people found commonalities, such as shared social and recreational preferences or life experiences, and established new relationships with their peers. When moving to care homes, most people were not able to choose who they would live close to. Relationships with peers could be both positive and negative, with others’ behaviour sometimes experienced as burdensome and generating a feeling of insecurity (Nygaard et al., 2020; Roberts, 2018).

People experiencing care have described how engagement in group activities can help build and maintain positive relationships with peers (Kang et al., 2020; Nygaard et al., 2020), generating a sense of belonging and purpose, and often providing a valued sense of contributing to the community by helping or advocating for one another. Dadswell et al. (2020), for instance, described how participatory arts activities enhanced social connectedness between people experiencing care, providing opportunities for meaningful contact, creative expression and developing friendships and fostering a sense of social cohesion and community, including for people with cognitive impairments. A sense of reciprocity was encouraged by providing opportunities for people to take on different roles and to support and praise each other. Similarly, research cited by Bethell et al. (2020) reports positive impacts of creative expression programmes on social connection.

Barriers to forming relationships can include cognitive, sensory and/or functional impairments, which can result in fewer opportunities to socialise and connect, often leading to disconnection and isolation (Abbott et al., 2018; Kang et al., 2020; Roberts, 2018). Other factors include the culture of the organisation, for instance, where people's physical needs and staff routines were prioritised over social needs, and a physical environment, such as the availability and organisation of communal spaces, which is not conducive to socialisation. Research indicates that people who are unable to mobilise independently have fewer friendships than those who can (Abbott et al., 2018). Lack of staff time to support meaningful interaction among people experiencing care can also serve as a barrier (Annear et al., 2017).

Factors which positively influenced the development of friendly relationships with peers included physical proximity, personality, and access to people with similar interests (Roberts, 2018). However, where people were unable to mobilise independently, these relationships were easily disrupted or stopped if people no longer had access to their friends, for instance due to a change in health or support needs (Roberts, 2018). Some people reported others, with whom they felt a connection, simply disappearing without explanation (Kang et al., 2020). A culture of care which supports and values people's social connections and preferences (Abbott et al., 2018) contributes to wellbeing and a sense of belonging, and enriches everyday life.

Not everyone valued developing relationships with peers (Roberts, 2018), with some preferring to spend most of their time alone.

New friendships can be facilitated by giving attention to commonalities between people, identifying shared areas of interest and introducing people to each other (Abbott et al., 2018). This requires staff to have knowledge of people's social preferences and interests in order to plan in a person-centred way, as well as considering how any impairments can be addressed to create optimal conditions for people to be socially involved. A physical environment which provides, where

possible, well planned indoor and outdoor spaces for socialisation helps foster relationships (Abbott et al., 2018). Staff can be intentional about where people are placed or spend time within the home to promote social interaction with peers with common interests, both on an individual and group basis, helping foster the development of friendly relationships which enrich everyday life (Roberts, 2018).

## Relationships with staff

The quality of relationships with staff is a key element in how people who live in care homes experience their daily lives, and a fundamental determinant for high-quality care (Baxter et al., 2021; Scheffelaar et al., 2018). People experiencing care have described various features of positive, responsive relationships with staff (Kang et al., 2020; Roberts, 2018; Scheffelaar et al., 2018), describing their relationships in terms of friendship, love and caring. These features included: staff who were friendly, genuine, and open; treated them with respect and dignity; had a positive and encouraging approach; were patient; and made them feel comfortable about needing assistance. People also valued when staff acknowledged them in personal ways which recognised their uniqueness, such as sharing individualised moments of fun and humour which both enjoyed (Roberts, 2018). Continuity of staff was particularly important for people; however, not everyone wanted or valued close relationships with staff (Roberts, 2018; Scheffelaar et al., 2018).

Relationships with staff which were characterised by mutual respect and reciprocity were stronger and promoted a sense of belonging and significance. Kang et al. (2020) described stronger social bonds between people experiencing care and staff where they engaged in more balanced social relationships, fostering a sense of greater independence. More reciprocal relationships are fostered when people experiencing care can share personal information and enjoy social conversation with staff both during and outside of care activities, where they wish to do so. Getting to know each other better promoted more person-centred care and provided opportunities for people experiencing care to share their skills, knowledge, and experience. Supporting people to make their own decisions wherever possible enhanced the quality of the relationship (Scheffelaar et al., 2018). Dadswell et al. (2020) described how engagement in participatory arts activities changed the relationship dynamics between people experiencing care and staff, where both were trying something new, promoting a greater sense of equality and reciprocity. Nygaard et al. (2020) also found that music and singing activities contributed to positive relationships, particularly where people were living with dementia.

Good relationships between people experiencing care and staff are vital for understanding people's preferences and values, and help support person-centred care (Abbott et al., 2018, Roberts, 2018). Consistent staffing and small group living

arrangements fostered the development of positive relationships, as people had greater opportunities to get to know each other.

The Covid-19 pandemic placed great pressure on staff, with multiple issues relating to staff levels being reported as well as changes in staff roles (Hanna et al., 2022; Sweeney et al., 2022). This led to high levels of stress, anxiety, and burnout among staff, who often felt unsupported (Giebel et al., 2022a; Hanna et al., 2022). Staff reported that the need for personal protective equipment, especially face masks, could hinder communication and relationships, impacting on the well-being of people experiencing care (Giebel et al., 2022a). Staff often found it difficult and distressing to try to explain to people why things had changed and why they were unable to see their families (Giebel et al., 2022a), or to try to implement guidance which they did not feel met people's needs (Hanna et al., 2022).

Frequent staff turnover and staff shortages was identified as a barrier to maintaining meaningful relationships (Kang et al., 2020) and encouraged task-oriented care which was not conducive to developing relationships. An organisational culture which prioritises routines and physical needs over people's preferences and psychosocial needs also acts as a barrier to facilitating meaningful engagement and interaction (Annear et al., 2017). Sensory, communication and cognitive impairments were also identified as barriers to satisfying interactions, and evidence indicates that if people are treated as though they are incapable of social interaction, they will quickly withdraw and cease trying (Scheffelaar et al., 2018). It is important therefore that staff have the skills, knowledge, and motivation to identify and address communication barriers.

Good relationships are fostered when staff know people well and recognise and acknowledge their uniqueness and their individual needs and wishes (Roberts, 2018). Consistent assignment of staff increases mutual familiarity, a sense of continuity and fosters more person-centred care (Kang et al., 2020), with better opportunity for social exchange during care activities. Opportunities to spend non-task-oriented social time together are valued by many people experiencing care, including participation in non-care related activities (Dadswell et al., 2020; Roberts, 2018). Supporting people to make their own decisions and share their skills, knowledge and life experience enhances reciprocity and improves the quality of relationships, as does enabling opportunities for them to carry out tasks helpful to staff, contributing to the life of the home. A sense of fun and humour and the use of non-verbal communication, such as touch, were valued by many people experiencing care (Scheffelaar et al., 2018).

## Relationships with the wider community

Connection with the world beyond the care home, whether through going outside or “bringing the outside world in” (Annear et al., 2017; Ciofi et al., 2022) contributes meaningfully to people’s wellbeing, personhood, and identity, and supports them to remain active citizens. Ciofi et al. (2022) identified the importance and benefits of “being out in the world” but noted how opportunities varied, often depending on availability of relatives or staff. Relationships with the wider community can bring benefits to both sides, fostering a sense of inclusion, belonging and reciprocity.

Research has explored other opportunities for social interaction and connection, for instance, through the large-scale use of student placements in care homes (Annear et al., 2017). This contact was seen by people experiencing care as meaningful and highly valued, with a strong degree of reciprocity as they were active participants in the students’ learning as well as deriving enjoyment from the interaction. A review of research on volunteering in older people’s care homes (Handley, 2021), including intergenerational contact, found that there were positive impacts on mood and engagement, but regularity and continuity was needed for these to be sustained beyond “in the moment” benefits. Abbott et al. (2018) discussed ways in which people who live in care homes can contribute to the broader community, generating a sense of inclusion and reciprocity. For instance, partnerships with schools and nurseries, whereby people spend time reading to children or hearing them read, can help make social connections and fulfil social needs.

Research on the role of visiting animals in care homes (Bethell et al., 2020; Jain et al., 2021; Pitheckoff et al., 2018) has found benefits for many people experiencing care, particularly those living with dementia. These included promoting increased social connection and interaction with peers and volunteers, connection to the outside world, and strengthening relationships with staff, as well as the enjoyment gained from physical and emotional interaction with the animals. The social benefits were reported to extend beyond the time of the visit, encouraging people experiencing care to share personal experiences and reminiscences, and helping residents and staff get to know each other better (Jain et al., 2021).

A culture which values social connection and seeks out person-centred opportunities for people both to go out into the world and to “bring the outside world in,” via reciprocal social interactions, contributes to wellbeing. Barriers to wider community relationships include person-specific factors such as people’s functional abilities/impairments, and service-specific ones such as staffing levels, the location of the care home, its resources, and the culture/values of the service (Ciofi et al., 2022). Covid-19 restrictions have, of course, had a profound impact on people’s opportunities to engage with the world outside the care home, although creative ways to maximise this can be found, such as the appropriate use of digital technology and optimising the use of outdoor spaces (Ciofi et al., 2022).

## The roles and involvement of family carers and why they matter

While the roles of family carers often change when a loved one moves into a care home, their involvement is no less important. Research has consistently shown (Kusmaul et al., 2022; Puurveen et al., 2018; Roberts et al., 2020) that family carers continue to provide a wide range of support which is vital both to their relative and to the life of the care home as a whole, and extends well beyond simply being a ‘visitor’ (Palattiyil et al., 2020; Sweeney et al., 2022).

Family carers are key partners in care (Hindmarch et al., 2021; Puurveen et al., 2018), supporting their relatives’ emotional, mental, social, and physical wellbeing, acting as advocates, communicators, and allies (Cornally et al., 2022), and often providing direct care. Their involvement is associated with better psychosocial wellbeing among care home residents (Roberts et al., 2020). They act as “guardians of the identity and dignity of their loved ones” (Lehto-Niskala et al., 2022).

The Covid-19 lockdown first declared in March 2020 has been described by relatives as an “abrupt rupture” (Avidor & Ayalon, 2022), involving an immediate forced physical separation between people and their families, with often profound consequences for both. Separation has been described as “difficult, frightening, frustrating and heart-wrenching” (Hovey & Shropshire, 2021), with family carers being unable or finding it far more difficult to maintain meaningful connections with their loved ones and carry out their previous roles (Cornally et al., 2022; Sweeney et al., 2022). Family carers felt the effects of the disruption in relationships on behalf of people experiencing care and themselves, often experiencing mental distress, guilt, anxiety, loneliness, frustration, and a sense of helplessness (Giebel et al., 2022b; Hindmarch et al., 2021; Palattiyil et al., 2020; Sweeney et al., 2022). The impact of this separation from loved ones has shone a greater light on the roles of family carers as essential care partners (Cornally et al., 2022; Corven et al., 2022).

### Social and emotional support

Family carers play a key role in meeting people’s social and emotional needs and maintaining personhood (Lehto-Niskala et al., 2022; Pirhonen et al., 2022). Meaningful contact with families represents “closeness, support, joy [and] natural togetherness” (Wallerstedt et al., 2018). It supports people’s sense of continuity and connection with their lives prior to living in the care home (Puurveen et al., 2018); their sense of identity, usefulness, control, and self-worth (Corven et al., 2022; Roberts et al., 2020); and promotes a sense of belonging and significance (Kang et al., 2020). Regular contact with family carers helps alleviate loneliness (Pirhonen et al., 2022), which research has shown is highly prevalent among people living in long-

term care (Budak et al., 2021; Gardiner et al., 2021) and is often enjoyable and satisfying for both parties, resulting in improved mood (Corven et al., 2022; Wallerstedt et al., 2018).

Many family carers have a vital role in facilitating social and community engagement, described as “being a link to the outside world” (Puurveen et al., 2018), supporting continuity and connection. This can include going out to familiar or new places; facilitating and nurturing relationships with wider family and friends; engaging in activities together; providing items of personal significance, and so on (Backhaus et al., 2020; Hovey & Shropshire, 2021; Lovatt, 2021).

Family carers often provide essential care and comfort when people are nearing the end of life (Barken et al., 2018; Wallerstedt et al., 2018), and this can be supported by clear, compassionate, and honest communication from staff, as well as practical help such as a physical space to stay overnight, and support for grieving.

Connection and communication can be more difficult when people are living with dementia (Corven et al., 2022) and a perceived decrease in mutuality and reciprocity in the relationship can be challenging for families, and for some, result in a decrease in visiting. Many family carers apply strategies to improve meaningful connection, such as undertaking activities together, where possible: for instance, going for a walk, looking at pictures, listening to music or doing domestic tasks (Corven et al., 2022). People experiencing care and their family carers have described the importance of face-to-face and physical interactions such as hugs and handholding for connection and emotional support (Chu et al., 2022a; Noten et al., 2022; Palattiyil et al., 2020). The lack of this contact during Covid-19 restrictions was a source of distress and was perceived by many to have impacted wellbeing and accelerated decline.

Often, family carers also contribute to the community of the care home and enhance the wellbeing of residents other than their own relative in various ways, for instance participating in leisure activities, social visits, fund-raising, and assisting residents when needed, augmenting roles typically performed by staff (Puurveen et al., 2018; Wallerstedt et al., 2018).

## **Advocacy and monitoring**

Many family carers take on a significant role in overseeing and monitoring their relative’s care, noting and reporting any concerns or changes (Fetherstonehaugh et al., 2021; Roberts et al., 2020; Wallerstedt et al., 2018), self-describing as their relative’s “eyes and ears” (Chu et al., 2022a). Some felt this vigilance was necessary to ensure their relative was being treated with dignity and respect and having their needs met (Puurveen et al., 2018), particularly when they lacked confidence in the quality of care (Tasseron-Dries et al., 2021). Some reported a need to advocate for

necessary action and “be the one that made things happen” (Wallerstedt et al., 2018). When unable to visit due to Covid-19 restrictions, many experienced significant concerns for their loved one’s wellbeing. They were no longer able to observe, for instance, the non-verbal clues that might convey something was wrong, which they felt staff may not have the time or personal knowledge to notice (Chu et al., 2022a; Fetherstonehaugh et al., 2021; Hovey & Shropshire, 2021). Some reported a decline in trust and satisfaction with their relative’s care home during the pandemic, with others expressing their shock at a perceived deterioration in their relative’s mental and physical wellbeing during the period of separation (Giebel et al., 2022b; Sweeney et al., 2022). People often noted a rapid cognitive decline which they attributed, at least in part, to a lack of cognitive and social stimulation (Chu et al., 2022a).

Family carers are an important source of information about people’s life histories, interests, values, and preferences (Backhaus et al., 2020; Puurveen et al., 2018; Roberts et al., 2020), particularly when people may not be able to supply this themselves, for instance due to dementia. This knowledge is invaluable in supporting staff to provide genuinely person-centred care and maintain personhood.

Family carers also mediate communication between their relatives and the staff (Kang et al., 2020; Roberts et al., 2020; Wallerstedt et al., 2018), advocating for and representing their wishes, preferences, and concerns: particularly where their relative was either unable or unwilling to do so themselves (Fetherstonehaugh et al., 2021).

Families have a vital role in decision-making and care planning, and frequently in overseeing and facilitating matters such as financial affairs, arranging and accompanying people to appointments, etc (Cornally et al., 2022; Wallerstedt et al., 2018).

## **Providing direct care**

Many family members play a vital role in direct care (Barken & Lowndes, 2018; Hovey & Shropshire, 2021; Puurveen et al., 2018), which includes essential activities typically assumed to be a staff responsibility, such as assistance with eating, personal care, and mobilising (Hovey & Shropshire, 2021). Research by Chu et al. (2022a) and Barken and Lowndes (2018) found that family carers, who are mostly women, reported providing a wide range of support with basic care, which was often associated with better outcomes for people (Wu et al., 2020), as well as alleviating pressures on staff (Chu et al., 2022a). For instance, one study found that where people required physical assistance with eating, nutritional intake was higher when assisted by a family member, illustrating the positive benefits of encouraging family carer involvement as active partners in care. Dedicated family support can make



mealtimes more enjoyable; often families have shared meals together for a lifetime, and this reinforcing of familial bonds can enhance the experience and result in improved intake as well as supporting the staff team (Wu et al., 2020). Similarly, a study by Morrison-Koechl et al. (2021) also found that higher social engagement was associated with better nutritional intake, concluding that strategies to better involve families and volunteers, particularly at mealtimes, were required.

Research has found that almost a quarter of family carers provide over 10 hours of weekly care to their relatives in care homes (Wu et al., 2020) and can typically dedicate more time to supporting their loved one than staff can. They have been described as the “invisible workforce” (Sweeney et al., 2022), providing essential care (Hindmarch et al., 2021). Not all family carers wish, or are able, to be involved in direct care, however, and not all people experiencing care want them to do so (Tasseron-Dries et al., 2021).

When visiting is restricted, families have expressed concern that not being there to assist may result in staff being overworked and less able to provide the level of care they expected for their relative. (Pirhonen et al., 2022; Sweeney et al., 2022). However, many have also expressed appreciation for the efforts and dedication of staff and concern for their wellbeing in difficult times (Hovey & Shropshire, 2021; Sweeney et al., 2022).

## **Barriers and enablers**

Several factors influence family inclusion and true partnership in care with staff. While family carers’ role is vital, they can occupy an ambiguous or marginal position in relation to staff (Backhaus et al., 2020; Barken & Lowndes, 2018), sometimes being regarded as outsiders and non-essential visitors (Chu et al., 2022a). The role of the family carer is not always straightforward (Hoek et al., 2021; Lehto-Niskala et al., 2022).

Partnership is difficult when power dynamics are uneven and family carers are not regarded as, or feel valued as, equal partners in care (Barken & Lowndes, 2018). This was exacerbated during lengthy periods of Covid-19 restrictions, when many family carers felt excluded, powerless, and entirely dependent on staff to facilitate contact with their loved ones (Chu et al., 2022a) and to communicate information and updates. Conflict and deterioration in the relationship between family carers and staff could occur (Giebel et al., 2022a), with both sides experiencing high stress and anxiety, and some family carers reported a feeling of “us versus them” (Chu et al., 2022a) rather than a sense of “being on the same team”.

Conflict can occur when expectations differ as to the role of family carers (Fetherstonehaugh et al., 2021). Many family carers have reported they are not

involved in decision-making, for instance, when care plans change, and do not feel they are part of a collaborative relationship with staff (Hoek et al., 2021; Puurveen et al., 2018). Evidence indicates that communication and trust between care home staff and family members is of great importance, and at the heart of positive relationships (Barken & Lowndes, 2018; Hoek et al., 2021); poor communication and a perceived lack of transparency by staff generates mistrust (Fetherstonehaugh et al., 2021; Pirhonen et al., 2022). Limited opportunities to speak openly with staff and be involved in decision-making can lead to miscommunication on both sides (Backhaus et al., 2020).

Families have expressed feelings that their knowledge and contributions are not wanted, valued, or respected, and their concerns not taken seriously or welcomed (Hovey & Shropshire, 2021; Puurveen et al., 2018). Some have expressed reluctance to voice concerns for fear their relative could be the target of reprisals, or that staff may feel attacked and view them as troublemakers or complainers (Hoek et al., 2021; Wallerstedt et al., 2018), resulting in some being invited to move their relative if they were dissatisfied, rather than working to address the concerns (Fetherstonehaugh et al., 2021; Puurveen et al., 2018).

Personal barriers to family involvement include factors such as geographical proximity to, and accessibility of, the care home, and the personal circumstances of family members which may limit their capacity to be involved (Roberts et al., 2020; Tasserou-Dries et al., 2021). Research has indicated that family involvement often tends to be higher where the resident's condition has deteriorated, or where relatives have concerns about perceived gaps in the quality of care (Puurveen et al., 2018; Roberts et al., 2020). By contrast, it may be lower where their relative is perceived as unaware or unresponsive, which is emotionally challenging for families.

Characteristics of homes which support family inclusion include an organisational culture where family carers feel welcomed into the home and enabled to spend meaningful time with their loved ones. This is encouraged by a physical environment which offers a range of indoor and outdoor spaces to facilitate interaction and socialisation, including opportunities for communal activities and informal contact and communication with staff (Barken & Lowndes, 2018; Hoek et al., 2021). Partnership, trust, and collaboration is supported by an ethos which values, welcomes, and supports family inclusion and collaboration, and is demonstrated by open and transparent, jargon-free communication; listening to and valuing family perceptions and expertise; ensuring avenues for and being responsive to concerns (Backhaus et al., 2020; Barken & Lowndes, 2018). Family inclusion is fostered by a person-centred approach which considers the personal circumstances and preferences of family carers (Tasserou-Dries et al., 2021). Partnership is also supported by policies and procedures, including staff training, which support and recognise the importance of family involvement, clarifying staff roles and responsibilities to include an understanding of families as equal partners, creating

mutual respect, and acknowledging each other's contribution (Hoek et al. 2021; Fetherstonehaugh et al., 2021). Research by Barken and Lowndes (2018) described a care service where all staff, including ancillary staff, were expected to develop and maintain a rapport with families from the point of admission, as a key part of their job description.

## The role of technology in facilitating connection

### Communication technology

Alternative forms of communication between family carers and people experiencing care become particularly important when visiting is restricted; however, even when this is not the case, in-person contact is not always possible due to geographic or other factors. "Virtual visits", largely through video calls (Kusmaul et al., 2022), while unable to fully compensate for physical visits (Noten et al., 2022), are a valuable means of connecting people to their families and friends; but various barriers and challenges exist (Chu et al., 2022b). Research has considered the use and effectiveness of different technologies as a means of communication and promoting meaningful connection (Chu et al., 2022b; Monin et al., 2020), while recognising that in-person communication remains the "gold standard" (Monin et al., 2020).

While video calls were a positive experience and a "lifeline" for some (Cornally et al., 2022), many did not find them to be effective (Hindmarch et al., 2021; Sweeney et al., 2022). Often, people experiencing care had cognitive and/or sensory impairments that prevented their effective participation in, or understanding of, calls (Avidor & Ayalon, 2022; Hindmarch et al., 2021), and the technologies used were often not familiar to older people (Giebel et al., 2022b) or readily compatible with their abilities and needs (Chu et al., 2022b). Virtual visits could also be associated with harm (Chu et al., 2022b; Palattiyil et al., 2020) as sometimes people were left confused, distressed, or anxious, and staff were not always available or able to help ease negative emotions (Cornally et al., 2022).

Not all services had access to appropriate resources or infrastructure, including a lack of the devices themselves and inadequate Wi-Fi/internet connections (Chu et al., 2022b; Palattiyil et al., 2020). Concerns about infection prevention and control also restricted distribution and sharing of devices. A lack of knowledge and/or forethought by staff could present a barrier; for instance, background noise affecting someone's ability to hear, staff not ensuring hearing aids were in (Chu et al., 2022b), or a lack of staff familiarity with how to use the technology (Giebel et al., 2022b).

For most, virtual visits were heavily reliant on staff availability (Chu et al., 2022b), and a lack of staff capacity often prevented calls taking place at convenient times, or

sometimes at all. The frequent need for a staff member to be present during the call also led to a lack of privacy (Noten et al., 2022).

The effectiveness of different methods varies depending on the individual. Monin et al. (2020) found that telephone calls were overall associated with more positive emotions than video calls, perhaps due to the technology being more familiar to people. Cornally et al. (2022) concluded that for some, both phone and video calls were ineffective due to sensory and cognitive impairments, and other methods such as sending cards and letters were preferred. Baxter et al. (2021) quote a resident who benefited from connecting with their family and community via technology, enjoying receiving photographs and messages from their extended family.

Technology has a significant role in facilitating and enhancing connection. However, it is not a universal panacea, but needs to be right for individuals (Noten et al., 2022; Palattiyil et al., 2020). It requires thoughtful approaches (Chu et al., 2022b) which consider co-ordination, support, adequate resourcing, and person-centred implementation, including consideration of potential harms. There is a need to support people experiencing care and staff to use technology effectively (Monin et al., 2020), establishing easy-to-use systems for people's preferred method. Digital communication is not a good fit for everyone, and more familiar communication methods such as phone calls, cards and letters are more appropriate for some (Noten et al., 2022).

## Other forms of technology

Other forms of technology can also play a role in fostering connection. For example, digital platforms such as social media can be a useful means, for some, of enhancing contact and information sharing (Hoek et al., 2021).

Reviews carried out by Neal et al. (2020) and Budak et al. (2021) regarding the use of technology for people living with dementia in long-term care, including multi-media computer programmes (such as reminiscence programmes) and robotic pets, concluded that technologies had the potential to enhance social interaction. However, they were only meaningful when specifically focused on enhancing social interaction and connection between people; for instance, by providing a cue for conversation or counteracting communication difficulties. These studies highlight the importance of using technology in a person-centred way, and as a means to facilitate connection between people rather than as an end in itself.

A review by Abbott et al. (2019) on the use of robotic animals ("robopets") among older people living in care homes, as an alternative to living animals, concluded they could have overall positive effects on health and wellbeing, promoting increased engagement and interaction, although were not suitable for or enjoyed by everyone.

Similar to interactions with living animals (Bethell et al., 2020; Jain et al., 2021), they had the potential to enhance social contact and interaction between people and with staff and family, and this was particularly notable where people were living with dementia.

Overall, new and old technologies can play an important role in facilitating connection; however, they must be applied thoughtfully and in a genuinely person-centred way, with adequate staff training and infrastructure to support effective use.

## Gaps in research/limitations

While some studies did include the views and experiences of people experiencing care, we found little available research which directly addressed their experiences during the pandemic. Some of the studies that included people experiencing care's voices were pre-pandemic. Most studies covering this period were carried out among family members and/or care home staff, perhaps reflecting the difficulty of engaging directly with people living in care homes during periods when visiting was restricted and foot fall in care homes was risk based.

The vast majority of literature concerned older people's care homes, with very few references to adults with learning/physical disabilities or mental health issues who live in care homes. While some of our findings are applicable to all people in adult and older people's care homes, it would be helpful if more research focused on the specific issues affecting other age groups.

## Conclusion

The findings from the review clearly demonstrate the vital importance of a range of meaningful social connections, including with families, peers, staff, and others, for people who live in care homes, and the variety of factors which act as barriers or enablers.

Supporting and facilitating meaningful connection must be a high priority for all those involved in decision-making which affects people living in care homes. There is no "one size fits all" solution for everyone, however; individualised, detailed, holistic assessment and personal planning is needed to ensure people in care homes experience genuinely person-centred care which meets their social needs, and is grounded in a respect for and safeguarding of their human rights.

By valuing what is important to people and taking the time to know what is working well, while ensuring staff understand the importance of personhood, each individual

can be kept at the heart of the process. Taking a human rights-based approach and respecting people’s views will also support people to be as active in their communities as possible, while upholding citizenship.

Through a person-centred approach to social connection that is rich in meaningful relationships, people living in care homes have the potential to thrive, and to enjoy a good quality of life.

While all people have the right to life, people living in care homes also need a proactive approach to ensuring their right to a private and family life is central to decision making. The review emphasises the vital importance of social connection to health and wellbeing, and how collaborative, relationship-centred communication and involving those who matter can not only improve people’s experiences but can also extend life.

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