

The experience of people moving into and living in care settings - a literature review.

Time to Connect (TTC) is a partnership initiative, supported by the Big Lottery Fund, between the National Development Team for Inclusion (NDTi) and Timebanking UK (TBUK). It aims to support people living in traditional care settings to increase their participation in and contribution to the life of their community.

Introduction

A review of literature helped us to understand Time to Connect in the context of other studies focusing on the experiences of people living in a care setting. A literature search was conducted using Web of Science. This is a multi-disciplinary research platform which enables simultaneous cross-searching of a range of citation indexes and databases in the sciences, Social Sciences and Arts & Humanities. It searches over 33,000 journals and therefore provides a broad overview of the current research base. The search criteria included articles published in the last ten years in the UK using the following combination of key words by audience with the care setting terms:

1. ["older adults" OR "older people" OR "over 65" OR "elderly" OR "senior citizen" OR "retired"] combined with ["residential care" OR "residential home" OR "retirement home" OR "nursing home" OR "care home" OR "Old people's home"].
2. ["learning disabilities" OR "intellectual disabilities" OR "learning disability" OR "Down's syndrome"] combined with ["residential care" OR "residential home" OR "retirement home" OR "nursing home" OR "care home"].

These two sets of search terms above were then combined with each of the following three terms to look at specific topics including:

- For moving into a care setting: "move"
- For community engagement: "community" OR "social inclusion" OR "activit*¹" OR "going out" OR "participation" OR "engagement" OR "involvement"
- For risk factors for loneliness: "risk factors" AND "loneliness OR isolate" OR "social exclu*"

It should be noted however that whilst a search was conducted for literature on both older people and people with learning disabilities, there was very limited results for people with learning disabilities, and there was very little about community activities; both are notable findings in themselves. The following bullet points summarise some of the headline findings about:

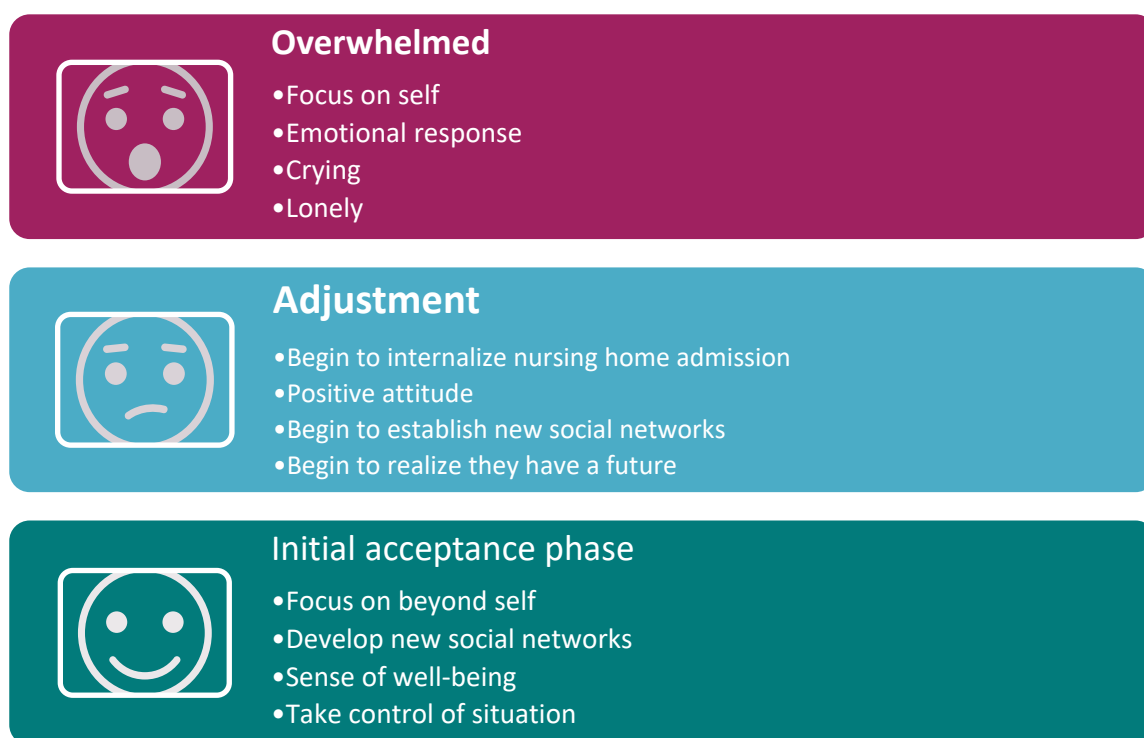
- the impact on residents of moving into a care home
- the factors that might influence an individual's motivation to take part in their community
- what can lead to social isolation and loneliness.

¹ * The asterisk is a truncation symbol used as a way of picking up a wider variety of options in a search. It represents any group of characters, including no character, for example activit* could include the word activity or activities.

The impact of moving into a residential care setting

- Research shows that older people fear moving into a care home because they fear losing independence and control of their lives. It is widely acknowledged that the experience can be an emotional and stressful time for older people, and this can be further compounded if older people are unable to exert autonomy and control over the decision to move in ¹.
- The physiological and psycho-social stress a person undergoes (recognised as Relocation Stress Syndrome as an official nursing diagnosis in 1992) in the transition into long-term care can present as anxiety, apprehension, increased confusion, depression and loneliness¹.
- The transition to nursing home life is different for everyone. In one article it is described a process with three phases: the overwhelmed phase, the adjustment phase and initial acceptance phase². See figure 1. Research found that people who had planned the admission adjusted at a faster rate than people who experienced unplanned admissions².

Figure 1. The transition to nursing home life – graphic adapted from A. Wilsons².



Living in residential care and the importance of:

1. Social connections and social capital.

- The ability of older residents to maintain meaningful relationships is an important determinant of the extent to which they can adjust to their new living arrangement. Older people who lose contact with important family and friends when moving into residential care have a higher risk of experiencing loneliness and social isolation¹.
- Social capital has been described as the ‘social glue’ that binds people together in families and communities, giving them a sense of belonging. It is developed in our relationships, doing things for each other and in the trust that develops as a result³. Evidence indicates that close personal relationships and connections with networks have a positive impact on health and well-being and that people with that have a wealth of this ‘social glue’ cope better with trauma⁴.

2. Autonomy and place to call ‘home’

- The psychological need for control over one’s life or autonomy is vital to wellbeing and personal development, including a determinant of motivation. Residential care facilities that provide environments that support autonomy have been shown to be positively associated with residents’ perceptions of such autonomy and increased psychological adjustment over a year¹.
- Our ‘home’ is fundamental to our identity, a place where we can express our individuality. Homely environments are connected to feelings of wellbeing. One report states that they are also places where older people say that they could make decisions about their lives, daily habits, have privacy, maintain and build relationships and engage in meaningful activity¹. Moving into a residential care home can therefore affect our sense of safety, identity and self-expression, which leads to this feeling of loss of control over life, and independence. Older residents who are dependent on care therefore benefit from support systems which maximise autonomy and relationships.

3. Having a sense of purpose and meaningful activities

- Self-actualisation is one our fundamental human needs. It includes the needs for freedom, choice, autonomy, control, privacy, productivity, self-expression and biography⁵. Fulfilment of this enables us to construct our sense of self and build self-esteem, which is important for our mental health.
- One study focusing on people living with dementia linked wellbeing to engagement in meaningful activity. People who were in the early stages of dementia put more significance on the everyday activities that had previously taken for granted because it was important that they were able to maintain continuity and they were able to contribute. This same study found that the values and beliefs which related to the resident’s previous roles, interests and routines were key factors that made activities meaningful⁶.

4. Reciprocity, contributing and community inclusion

- Older people consider reciprocity a positive trait which in turn helps maintain self-esteem. Research showed that older people found ways to counteract feeling dependent and found balance in relationships by reciprocating care to others either financially or emotionally. Gaining support from their local community encourages older people to have a sense of belonging⁷.
- For people with learning disabilities the studies that have focused on inclusion in terms of community engagement or social networks showed that people who had lived longer in the community had a greater community involvement, the opposite was found for people in segregated settings. People with more complex needs and those who were older were more at risk of being excluded⁸.

Key factors that can lead to social isolation

- Social isolation occurs in the absence or reduction in social interactions. Loneliness is the subjective experience that occurs when the desired social interaction does not match the actual interaction⁹. Loneliness is a risk factor for poor health and wellbeing including low self-esteem¹⁰ and depression¹². Social loneliness (the absence of a wider social network) can lead to feelings of boredom and exclusion. Emotional loneliness (the absence of an intimate relationship) can lead to distress and apprehension¹¹.
- Older people (particularly people with dementia) and people with a learning disability are more vulnerable to experiencing loneliness and social isolation^{9,12, 15}. Whilst there are some commonalities, there are also some factors that are unique to each group:
 - **People with a learning disability** generally have a much smaller social network compared to the general population. Difficulties in communication, processing information, understanding and perspective taking may cause skill impairments which makes building social connections more difficult. Problems associated with behaviours that challenge and difficulties in initiating self-directed activities which means that people spend their free time alone and engage in passive activities, can for some people also contribute to becoming socially isolated and lonely¹².
 - There is a wealth of research on loneliness and **older people**. These studies consistently report the impact that life events such as poor health, moving after retirement and loss of a partner, have on social interactions and therefore susceptibility to loneliness. Other factors associated with loneliness include age, gender, childlessness, poverty, education, income, environment, cognitive function, anxiety, and depression.

These risk factors have been described in the context of an ecological framework that views the interaction of multiple factors across four levels: individual (personal characteristics and life course transitions); relationship (personal relationships and social networks); community (the type of neighbourhoods and activities available in the community) and societal (discrimination, inequality, lack of social cohesion). This illustrates the complex nature of loneliness and the need to find multiple solutions although studies have shown that successful interventions to address loneliness include adaptability, community participation and activities involving productive engagement^{9, 13, 15}.

What can we conclude about the evidence in relation to Time to Connect?

- It's clear, certainly for older people, moving into a residential care home is an emotional and challenging time, made worse for those who have not been involved in the planning or decision making. It takes time to adjust but there are a number of factors that are important not only in making the transition easier but the creation of a place residents can lead a good quality of life and call home. These are: building social connections; having autonomy and understanding the values and experiences of the individuals; providing opportunities for meaningful activities with purpose; and where people can make a contribution and be included in their community. These are the same factors that are central to the outcomes of Time to Connect. This reinforces the importance and relevance of this work in residential care settings.
- In addition to corroborating on what residents in care settings need to live a good life, some of the studies mirrored other findings of the Time to Connect evaluation, namely:
 - The importance of staff building relationships with residents, providing opportunities to talk about their feelings, taking time to hear about their values, experiences and interests, acknowledging and celebrating that person's life and their achievements and then supporting their aspirations regarding their future.
 - In one study¹⁴ residents were unable to engage in meaningful activities because the care home was under-resourced, and staff were unable to meet both basic and higher needs. Activity and meaningful occupation was not seen as part of the everyday routine, rather as something separate that required support from additional staff who could co-ordinate activities in the home. There was mixed picture in some staff recognizing the importance of meaningful activity and wanting to see this included in their role and others that had the view that older people in residential care didn't want to or couldn't engage in meaningful activities. From these findings researchers suggested staff attitudes may be a barrier for residents to engage in meaningful activities. They referenced work on culture change in care homes and the need to review how older adults are perceived, promote care practices based around relationships, give a voice to all stakeholders and have strong leadership¹⁴.
 - Clearly more research is needed into the experiences of people with learning disabilities moving into or living in residential care.

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