MY HOME LIFE

Our vision is a world where all care homes are great places to live, die, visit and work.

Maintaining identity

This updated research briefing paper was written by Aisling McBride and based on a review of the literature on quality of life in care homes, undertaken by the National Care Research and Development Forum in 2006¹, which was later updated by a review of reviews (2006-2016), undertaken by the My Home Life team. My Home Life is an international programme of work aimed at promoting the quality of life for those who are living, dying, visiting, or working in care homes for older people.

Overall, research on maintaining identity seems to reflect many of the findings of the original review (NCHRD, 2007). Post 2007, new evidence suggests:

- Psychosocial interventions help staff seeing beyond the disease (Lawrence et al 2012).
- A clearer evidence base that supports the

Introduction

Maintaining a sense of identity is linked with positive self-esteem and perceptions about quality of life (Davies 2001; Tester et al., 2003; McKee et al., 2005). Intrinsic to this personal sense of identity are aspects of gender, occupation, ethnicity and sexuality. Yet living in a care home can undermine the sense of identity. It is easy for long-term care facilities to afford few links with a resident's personal or cultural past (Chaudhury, 2003). In addition, a number of other factors may impact on a use of reminiscence therapy/psychosocial interventions in a range of care setting to improve quality of life and improve symptoms of loneliness, anxiety and depression (Huang et al., 2015; Bohlmeijer et al., 2007).

- No adverse effects reported from reminiscence therapy and clear support to recommend this intervention (Elias et al., 2015).
- Life story is a particularly importance psychosocial intervention in improving quality of life in care homes (Bohlmeijer et al., 2007).
- A clearer evidence base to support participatory arts activities enhancing person-centred approaches to care (Fraser et al., 2014).
- There is a need to focus on psychosocial needs as well as physical needs in individuals with dementia (Cadieux et al., 2016).

person's ability to maintain a sense of identity including: loss of health and/or cognitive ability restricting a person's independence and self-realisation (Forte et al., 2006; Tester et al., 2003).

The process of moving into a care home can have a number of negative impacts on an individual's sense of self and personal identity, for example:

• The relative absence of private physical space in which to undertake intimate activities;



¹NCHR&D Forum (2007) My Home Life: Quality of *life in care homes – Literature review, London: Help the Aged.*

- The provision of communal facilities and institutional routines;
- The loss of the ability to attend their usual place of worship or other meaningful places;
- A sense of continuity and selfhood which defines the person in their community may also be lost in the transition into a care home resulting in a loss of the person's sense of identity. (Ashburner, 2005; Forte et al., 2006; Chaudhury, 2003).

In response to recognising the importance of maintaining the person's sense of identity and the potential risks involved in moving into a care home, a number of good working practices have been developed to safeguard the older person's sense of self and personal identity. These include the use of the person-centred approach to care, biographical work, and the need to involve the wider community. These will be discussed in more detail below.

Person-centred care

Person-centred care aims to work in partnership with the older adult, valuing them as individuals and providing care which meets their needs and not those of the institution. Fundamental to delivery of person-centred care is the establishment of effective relationships, which enable the individual to feel as a valued member of the care home community (Li and Porock, 2014). Person centred care is one of the standards of the National Service Framework for Older People (Department of Health, 2001) and encompasses four elements:

- Valuing people and those who care for them;
- Treating people as individuals;
- Looking at the world from the perspective of the individual; and
- Providing a positive social environment in which the person can experience relative wellbeing. (Brooker, 2004)

Li and Porock's (2014) review outlined and compared models of person-centred care. They highlight the need for staff training on person-centred care, which was found to significantly reduce behaviours that can be challenging in residents living with dementia. However, they also found mixed results, when exploring the impact on residents living with depression alone.

Biographical work

Understanding what matters to the individual, including his or her values, beliefs and wishes, is the key to person-centred care. Biographical work can be therapeutic for the resident while at the same time enabling staff to get to know individuals well and to work with them to tailor the care provided (Goldsmith, 1996).

Many older people experiencing chronic illness and disruption of their former life patterns need help to reflect on the past and find meaning for the present (Sidell, 1995). It is therefore important to provide opportunities to re-identify as people. Taking a biographical approach aims to understand what matters to each individual (Wells, 2005).

A biographical approach is also about involving the resident and their family in the process of gathering and reviewing information about their needs and wishes in the care home, and in the negotiating how this is to be delivered to ensure it is helpful and appropriate (Davies, 2001; Wells, 2005). It can include sharing memories, life stories or autobiographies, oral history and life review (Goldsmith, 1996). Provided that staff have the necessary time, skills and training to carry it out, reminiscence activity is powerful in maintaining identity in older people, as well as allowing a relationship to develop between residents and staff. In addition, everyday talk about the past, enabling older people to preserve their identity can lead to intergenerational benefits (McKee, 2005). Bohlmeijer et al. (2007) found in their review on reminiscence for older adults that the intervention had a moderate influence on life satisfaction and emotional well-being, with the impact being greater



for community dwelling older adults compared with those living in nursing homes. Life review, in particular, was found to have a greater impact than reminiscence therapy.

Similarly, Huang and colleagues (2015) carried out a meta-analysis of reminiscence therapy, testing the hypothesis that such interventions improve cognitive functions and reduce depressive symptoms. Their review focussed specifically on older adults with dementia. They found that reminiscence therapy has a small impact on cognitive impairment and moderate impact on reducing depressive symptoms in individuals with dementia.

Elias et al (2015) also found that reminiscence therapy reduced depression, as well as significantly improving anxiety symptoms and had a short-term impact on reducing the feeling of loneliness. They reported no adverse effects. Reminiscence therapy was recommended as a worthwhile treatment for older adults (Elias et al., 2015; Huang et al., 2015).

Ways of achieving both a biographical approach and person-centred care include:

- Use of good communication skills, including actively seeking out the individuals ambitions and exploring how best to meet them. This is essential, but not always straightforward. A dialogue can be developed with residents through listening, observing non-verbal signs, using other communication aids such as photographs or personal objects to act as cues, and having visitors to help develop conversation and interactions (Wells, 2005).
- Consistent staff assignment has been found to be important in making it more possible for staff and residents to get to know each other. Staff are potentially able to observe the time of day when an individual expresses her-or himself best and the activities that stimulate conversation (Davies, 2001; Allan, 2002; Tester et al., 2003). Paying attention to environmental conditions such as noisy rooms

is particularly important for those with sensory impairment (Cook et al., 2006).

While in the original review (NCHRD) there was a lack of research supporting the use of person-centred care and biographical approaches, the review of literature reviews (2007-2017) documents benefits of psychosocial interventions discussed in relation to people with dementia and care staff. Cabrera et al (2015) found psychosocial interventions have the potential to improve quality of life and quality of care for people living with dementia in care homes. They added that the activities should be tailored to the resident's characteristics to achieve effectiveness.

Fraser, Bungay and Munn Giddings (2014) offer further tentative findings from their review, suggesting participatory arts activities add meaning to residents' lives, increased engagement and emotional involvement, have a lasting effect on positive mood, improve memory recall and caregivers impression of well-being. However, the review conducted by Malderen, Mets and Gorus (2013) reported no systematic effects on quality of life and reminiscence therapy, adding that impact on quality of life was ambivalent and contradictory.

Cadieux, Garcia and Patrick (2016) focusing on the needs of people with dementia, identified a need to move from structured to flexible approaches to care. Trahan et al (2014) additionally indicate the necessity of making modifications to foster activity engagement. They found a growing evidence base for different modifications to foster engagement and reduce behavioural and psychological symptoms in people with dementia. Modifications made to objects and property, were positive and support the person-centred care model i.e. personal information matched to meaningful interventions increases engagement.

Involving the wider community

Involving key people and groups from the local community is also valuable. In one home mentioned in the literature, community education workers were invited to meet residents to discuss their interests and



to run community education classes in the care home that were open to residents and other members of the community (Lewin, 2002). Exploring ways for residents to link with the wider community can also be achieved by enabling them to join relevant groups to participate in community activities that interest them. In addition, the internet allows an individual to reach out from a care home by enabling links with the wider community and maintaining relationships with family and friends (Baun and McCabe 2000; Klein and Jess, 2002). Some areas provide training for older people to develop their computer skills (Wilson, 2004). Enabling individual residents to contribute to care home life and local community, if they wish, is valuable in promoting identity (Wilson, 2004). In one example from the literature, a resident offered to meet new residents as part of their orientation to the home. In the same home, it was proposed that residents should visit local schools to talk about their lives and that the home should produce a leaflet offering a list of interests and topics about which residents might wish to speak (Lewin, 2002).

An important role for staff is supporting residents to make new friendships and sustain current ones by introducing them to people from similar backgrounds or interests, welcoming existing friends and families when they visit, or supporting residents to write letters or telephone to stay in touch (Cook et al., 2006; Cook, 2006). Strong family relationships and friendship networks can help to maintain identity in a care home and care home staff can support this by enabling a welcoming environment.

Staff support

Developing person-centred care, whilst immensely rewarding, can also provoke anxiety and discomfort as staff come to terms with the emotional nature of their work. Care that is not person-centred (e.g. task orientated practice) can result from individual and organisational psychological defences to protect staff from the pain and anxiety associated with emotionally traumatic nursing work (Menzies, 1977). Establishing person-centred care must include a great deal of support for staff in addressing these anxieties and breaking down these defences. As well as training managers and staff to develop new knowledge and skills, other forms of support may be needed. In one study, this included group clinical supervision for all staff, action learning for senior nursing staff and dementia care mapping (Ashburner, 2005).

Staff need to be supported in taking on board psychosocial aspects of care, creating space for reflection, recognising and valuing the work they do and giving staff ways of dealing with the difficulties of the work they do (Cotter 1998; 2002a, 2002b).

Working in partnership in this way may require greater support for those in a leadership position, because staff becoming empowered to voice their different views may lead to conflict that the manager may feel ill-equipped to resolve (Cotter, 2002a).

Good practice suggestions

The review of reviews (2007-2017) highlighted various good practice points for supporting care homes residents to maintain a sense of identity. Below is a list of such points:

- Enable choice and control over personal space, property and appearance: Residents should be able to decide how they dress, choose items they will bring into the home and have control over personal space (Tester et al., 2003). They should feel able to exercise choice and control and take on some of the tasks of the home such as showing around visitors (McKee et al., 2005). It is essential to strike a balance between secure storage of personal possessions, such as jewellery, with resident's wishes to be able to use them when they want. This requires vigilance from staff and appropriate policies to be in place.
- Establishing a forum for residents and their families. Outcomes from a forum in one home included setting up new services such as chiropody



and environmental improvements, including an improved door entry system (Ashburner, 2005).

- **Recognising ethnic and cultural needs.** This could involve recruiting staff from different ethnic groups to reflect the local population; staff training on cultural diversity; availability of translation services; providing washing and toilet facilities for particular purposes; potential for segregation of male and female quarters; considering areas relating to food storage, preparation and cooking (Mold et al., 2005b; Institute for Jewish Policy Research, 2002).
- **Recognising spiritual needs** may mean providing places for prayer and meditation; arranging for clergy and others from different religious institutions to visit; enabling residents to attend places of worship or religious events outside the care home or staff training on spirituality (Orchard and Clark, 2001; Sapp, 2004; Johnston and Mayers, 2005). Spirituality may not be the same as following a religious faith, although for some people this is their path (Coleman, 2004).
- Meeting more general spiritual needs can include involvement in reading, expressive arts, music, walking or gardening. Some reports argue that the spiritual needs of older people with dementia merit a particular focus. Involvement in creative arts can enable communication, expressiveness and continuation of personhood. For example, listening to classical music may touch a chord deep within a person (MacKinlay, 2004; Killick, 2004; Read et al., 2003).

- Offering couples space for intimacy and privacy and using skilled observation and emotional literacy to understand their needs will help residents feel they have the right to express their sexual identity (Heymanson, 2003; Springfield, 2002; Hurtley, 2005).
 A sensitive and respectful approach will be needed from staff to ensure that one person's need for sexual expression does not lead to coercion of vulnerable others (Forte et al., 2006).
- Communication with residents can be resource intensive. The use of external advocacy schemes to supplement the time provided by care home staff can be beneficial.



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