



**Older People's Commissioner for Wales**  
**Comisiynydd Pobl Hŷn Cymru**

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# **A Place to Call Home?**

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**Literature Review**



# The Older People's Commissioner for Wales

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales. The Commissioner and her team work to ensure that older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services that they need.

The Commissioner and her team work to ensure that Wales is a good place to grow older, not just for some but for everyone.

## How to contact the Commissioner:

The Older People's Commissioner for Wales  
Cambrian Buildings  
Mount Stuart Square  
Cardiff  
CF10 5FL

Phone: 08442 640 670

Email: [ask@olderpeoplewales.com](mailto:ask@olderpeoplewales.com)

Website: [www.olderpeoplewales.com](http://www.olderpeoplewales.com)

Twitter: [@talkolderpeople](https://twitter.com/talkolderpeople)

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# Introduction

There are over 23,000 people living in residential or nursing care homes for older people in Wales. Reasons for admission are varied and in part serve to identify a need to acknowledge the complexity of individual resident's requirements. These range from complex health needs to frailty and an inability to continue to live independently in one's home.

The figures around life expectancy of older people in residential and nursing care are contested; however, average life expectancy of an older person admitted to a care home that offers personal care is between 2-3 years and 1-2 years in a nursing home (Goodman, 2011). Others refer to a median life expectancy of approximately 15 months (Forder et al, 2011; Horlick, 2013; British Geriatrics Society, 2012). While approximately 27% of older people live in care homes for more than three years (Forder, 2011).

Older people enter residential/nursing care for a variety of reasons, in recent years a determining factor has been the increasing prevalence of Dementia. Dementia is a primary reason for admission into residential care homes accounting for 37 to 40.0% of all admissions (Ellis-Smith, 2014).

As the ageing demographic grows, so demand for care home places will increase, placing mounting strain on existing services (Forder et al, 2011). Indeed, the UK Government recognises that the impact of demographic change across the UK (including an ageing population, expanding numbers of very old people and changes in the willingness of family members to provide informal care for elderly relatives) has placed a strain on social care services and increased demand for residential care. "This demand is expected to continue to grow: the number of people in care homes is projected to rise from 345,000 in 2005 to 825,000 in 2041" (Gheera, 2010). Because of this there is an urgent need to ensure that the future of residential care is in safe hands and providers offer the best possible quality of life and care to all residents.

There are of course many examples of excellent quality of life and care (Owen and Meyer, 2012). The Social Care Institute for Excellence (SCIE) recognises this and defines the delivery of quality of life, and care, in care homes as the ability to fully embrace "effective leadership (showing that the power balance shifts from the professional to the individual) and person-centred/relationship-centred care. Such care homes respect dignity and human rights and seek to actively involve people receiving the service, and their carers. In addition, teamwork and effective communication, staff development programmes and robust systems of quality assurance contribute

to positive outcomes for individuals” (SCIE, 2009). However, inconsistency, in the delivery of quality of life and care for older people in care homes in Wales is an issue that has been consistently raised with the Older People’s Commissioner for Wales.

This literature review forms the first part of the Older People’s Commissioner for Wales’ review into the quality of life and care in residential care homes across Wales and will seek to deliver an initial base of evidence about what quality of life and care means to older people living in care homes. It will seek to identify what the existing literature tells us about quality of life and care in all care home settings and determine what factors have an impact on the quality of life of older people.

This literature review is set out in three parts:

**Defining Quality of Life**

A look at the meaning of quality of life.

**What the literature is telling us?**

An examination of historical and current thinking and practice

**The Landscape in Wales**

A look at programmes and legislation specific to Wales

## Key points to note:

1. The literature relating to quality of care in care homes tends to be generic, discussing older care home residents as a homogenous group rather than taking an individual or a culturally and/or socially nuanced approach
2. In general, few studies make a distinction between nursing and residential homes, using the umbrella term 'care homes' to encompass both
3. Transfer into residential care is a key area with over 50% (UK) of care home admissions coming from hospitals
4. Partnership working appears largely to occur by default at present (Szczepura, 2008). There is opportunity for a more strategic approach to providing support in residential homes
5. Whilst black and minority ethnic issues and lesbian, gay, bisexual issues represent 10% of the literature reviewed, these groups were specifically targeted. Therefore, 10% is not an accurate reflection of total existing literature and these themes are not widely covered in the general literature.
6. No information relating to transgender issues and care homes was sourced.
7. There are particular shortfalls in the literature relating to spiritual and religious issues, disability and learning disability, sensory loss, administering of medicines, gender differences and the use of Welsh language.

# Defining Quality of Life

Much of the literature refers to the clear distinction between “quality of care” and “quality of life.” Good quality of care, whilst important, does not necessarily result in good quality of life. Conversely, poor quality of care does not necessarily result in poor quality of life. So, what is quality of life and how is it defined?

Answers to this can be somewhat subjective as there is no definitive consensus on what ‘quality of life’ is, with the concept being variously described as “confusing, elusive, controversial, and lacking clarity” (Ettema et al 2005). However, one thing is quite clear, quality of life is not a static concept; rather, it shifts with a number of meanings tailored to individual perceptions.

One of the difficulties in trying to define quality of life stems from the subjective/objective nature of the term. Lawton (cited in Thompson 2005) concludes that quality of life assessment should include both subjective and objective factors. Lawton outlines four dimensions of quality of life as:

- Psychological well-being: affective states including depression, anxiety, agitation, happiness and contentment
- Objective environment: refers to structured or routine events and includes architectural environmental features
- Behavioural competence: refers to a person’s behavioural abilities including functional ability, physical health, behaviour and cognitive ability
- Perceived quality of life: the person’s own perception of their quality of life

In recent years, the term “quality of life” has come under increasingly close scrutiny by the World Health Organization (WHO) (Warner et al 2010). Based on a wide-range of definitions, WHO has defined quality of life as being made up of the following core domains:

- Physical;
- Psychological;
- Level of independence;
- Social relationships;
- Environment;
- Spirituality, religion or personal beliefs (WHOQOL, 1998)

WHO's definition is quite broad but is underpinned by "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL, 1995).

For WHO, and for the purposes of this literature review, quality of life at its core is "about the subjective experiences of the individual concerned and how their life compares with their hopes and expectations" (Warner et al, 2010).

# What the literature is telling us

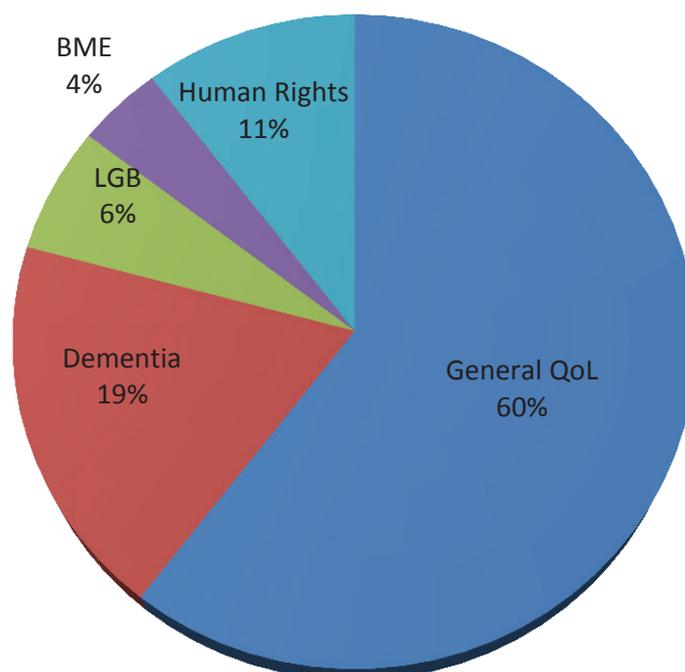
## Main Themes

The main themes identified in the literature reviewed relate to:

- General quality of life issues<sup>1</sup>
- Dementia and cognitive impairment issues
- Human rights issues
- Lesbian, Gay, Bisexual (LGB)<sup>2</sup>
- Black, minority and ethnic issues (BME)<sup>3</sup>

The following pie-chart illustrates what percentage of the literature reviewed each of these main themes represent:

### Themes



<sup>1</sup> General QoL refers to generic studies that cover all aspects of quality of life for all older people in residential care without referring to specific groups or issues.

<sup>2</sup> Transgender issues were to be included in this topic; however, I have been unable to source any transgender literature in the review so far.

<sup>3</sup> Although issues relating to BME, LGB comprise of 10% of the total literature in this literature review, it should be noted that a targeted effort was made to locate literature specific to both areas. 10 % of the overall is therefore not truly representative of the total output of QoL in care homes related literature. The shortfall has been noted in the literature and it is recommended as part of this literature review that more specific research is needed in both areas.

# General Quality of Life

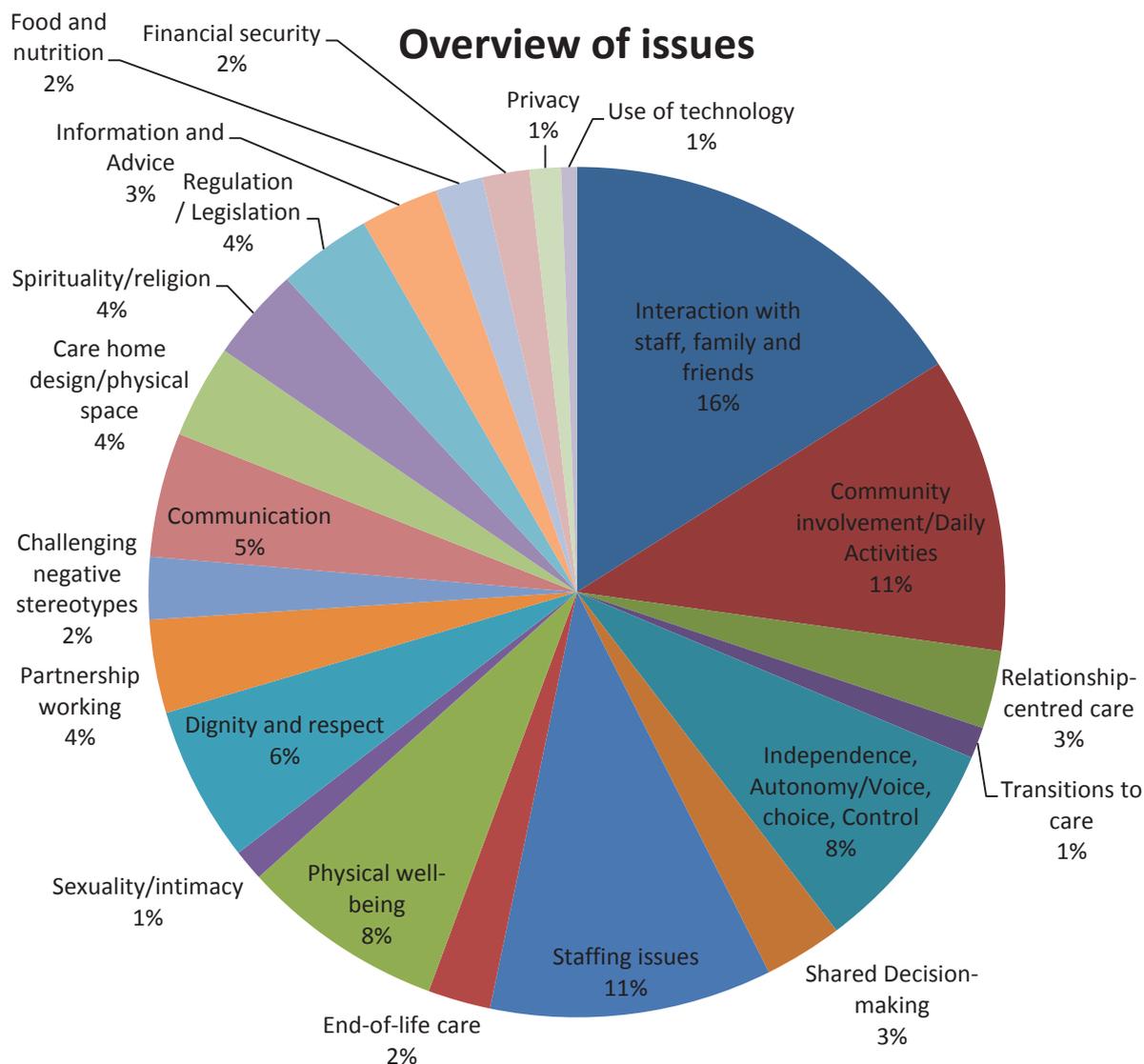
The majority of the literature relating to quality of life in care homes takes a homogenous approach, tending to look at quality of life for all older people in care homes rather than focusing on specific groups or indeed specific types of residential care. This generic approach identifies a number of recurrent themes, which will be discussed in more detail later; however, these have been condensed down to three broad umbrella headings identifying what makes good quality of life in a residential care home setting:

- Environment
- Activities
- Relationships (Reed in Meyer, 2007)

Broadly speaking, these three headings have been identified as key to maintaining (and improving) quality of life (QoL) by some of the predominant drivers in the field. Of particular note is the work of Tom Owen and Prof. Julianne Meyer (My Home Life) and Prof. Mike Nolan (The “Senses Framework” – see Appendix 1). The Commissioner’s “Quality of Life” model, developed by speaking directly to older people, significantly overlaps with this work. The table below provides an illustration of the Commissioner’s QoL model as it relates to the driving principles of Owen’s/Meyer’s and Nolan’s work:

<b>Commissioner’s QoL Model</b>	<b>My Home Life</b>	<b>The “Senses Framework”</b>
<b>I have voice, choice and control</b>	Maintaining identity	Significance
<b>I live in a place that suits me and my life</b>	Creating community	Belonging
<b>I can get the help that I need</b>	Adequate healthcare responses	Continuity
<b>I feel safe and listened to, valued and respected</b>	Shared decision making	Security
<b>I feel my life has value, meaning and purpose</b>	Promoting a positive culture	Achievement
<b>I can do the things that matter to me</b>	Shared decision making/ Promoting a positive culture	Purpose

Under the broad umbrella themes sit a much wider range of specific issues. The following pie chart identifies these and illustrates what percentage of the literature reviewed each issue represents:



These specific issues can be grouped into two distinct groups providing a clearer idea of what the literature is telling us:

- Issues directly impacting residents QoL; and
- External factors affecting residents QoL.

The issues outlined below occur frequently in a broad selection of the literature.

# Issues directly impacting the QoL of residents

## Interaction

The Joseph Rowntree Foundation (JRF) argues that care homes are “uniquely placed to help older people maintain their personal identity because staff have the opportunity for regular interaction and engagement with the older people they are supporting over a sustained period of time” (JRF, 2012).

This is particularly relevant where older people struggle to articulate their views and needs due to mental and physical frailty or low self-esteem. It has been understood for some time that interaction is crucial to developing and maintaining a good quality of life.

A great deal of research over the years has illustrated the importance and influence of social interaction on the health and quality of life of older people in residential care, including life satisfaction and emotional, subjective and psychological well-being (Leefer 2014; Haugan et al, 2013; Holmen et al.1994; Lee and Shehan 1989; Traupmann et al. 1992).

Older people themselves have identified social relationships and social contacts with family and friends as important influences upon their quality of life (Bowling 1995; Farquhar 1995); and peer relationships are perceived as vitally important in the ageing process (Jerrome 1992). Research has also shown that within institutional care settings social relationships among older people play important roles in supporting and helping residents (Oleson et al 1998; Powers, 1988).

Despite this, findings of quantitative research consistently report that institutional care settings are bereft of high levels of social interaction and social activity (Hubbard et al, 2003). Interaction with other residents and/or staff is therefore recognised as vital in supporting a good quality of life (Cook, 2009). Older people are particularly vulnerable to social isolation or loneliness owing to loss of friends and family, mobility or income (Windle, 2014). Encouraging and supporting close relations has the added advantage of combating loneliness.

## Daily activities

Research has shown that meaningful activity, recreational opportunities, expressive arts or one-to-one activities can make a significant contribution to the overall living environment in care homes (Corbett, 2013). Care home residents may need to continue past activities or to begin new ones (Cutler, 2011). This support needs to be carefully planned and discussed with

residents. Daily activities can also mean residents having access to social networks.

There is increasing recognition of the benefits for everyone of having the chance to take part more actively in the arts and the impact of participation on our physical and mental health and well-being (Hayes & Povey, 2010). However, recreational and educational activities in the care home need to be flexible and adaptable to the changing needs of residents and their family members.

It is important to note that “activity” does not simply mean recreational activity for which the occasional game of bingo, or a quiz may be thought to be sufficient but; as the College of Occupational Therapists (COT) stress, activity is about “everything we do.” To be emotionally and physically well we need to actively participate in daily life. “This is not an added bonus of good care but an essential requirement. When a person is left to sit for most of the day with little movement or stimulation a number of detrimental physical and psychological changes can occur” (Tancock, 2013).

## Community

“If nursing homes are to lose the perception that often they are just living graveyards for people at the end of the line, [a] sense of community and co-operation needs to be highlighted” (Titmus in Owen[ed], 2006). The loss of ties to the communities that an older person has been part of can be hard to bear.

Creating a sense of community within a care home is therefore a goal to which residents, their families and staff can all aspire and contribute (Owen [ed], 2006). Homes can seek to produce a sense of community to which residents, their families and staff contribute. This, in turn, can result in community belonging and satisfaction – key factors in supporting good quality of life (Owen & Meyer, 2012).

## Independence and autonomy

Autonomy can be defined as the freedom to choose and to live with dignity, privacy and independence. It is a key concept in the rights that should be accorded to service users (Hodgson, 2013). Autonomy covers a range of choices, including:

- How the person wishes to be addressed
- Times of going to bed and getting up
- Menus (Food and Drink – availability and choice)

- Use of time (e.g. recreational activities)
- Furnishing a bedroom
- Who to associate with

Staff providing personal care should never make the mistake of assuming that because they know the individual well, they always know what their preferences will be. Choosing what to wear, what to eat or drink or where to spend their time in a residential home are all examples of how people can retain autonomy over key aspects of their daily lives, even when they have complex needs and require a high level of support (Breen, 2009).

Service providers in care homes should foster an environment in which residents can maintain their independence wherever possible. (Hodgson, 2013)

## Physical Health

Many older people who live in care homes have high levels of health care needs (Martin et al, 2011). Some reports have suggested that three quarters of people in care homes have a disability. Others have found that 57% of women and 48% of men needed help with one or more 'self care' tasks (Williams, 2005). Physical health is fundamental to quality of life.

Health can be promoted by spending time in personally meaningful and enjoyable ways, socialising and sharing, physical activity and exercise, and learning. Older people have substantial and complex healthcare needs which require the full range of services. Despite this, evidence suggests that these individuals are not receiving the healthcare services they should, and in some instances are paying for services that should be provided under the NHS. (My Home Life Cymru)

## Religious/Spiritual Needs

Spirituality, although a contested concept, is evolving and developing and can be defined as a search for meaning with or without religious adherence. Person-centred care involves spiritual care – the time, attention and listening to support individuals to find meaning and purpose in their lives. It has been established that there are a range of activities and practices which can support these dimensions of spiritual care (Mowat, 2013).

Enabling residents to experience a more stimulating and purposeful life that encompasses their religious and spiritual needs is important in supporting good quality of life (WHO, 1998). This also requires a degree of knowledge, sensitivity and understanding on the part of care home staff in order to cater

to the spiritual and religious needs of individuals.

## Involvement in Decision-making

All residents (including those with cognitive impairment), their families and staff members need to have the opportunity to be involved in the decisions that affect them, to the extent that they wish to be involved (Owen & Meyer, 2012). Feeding the views of residents and relatives into a change process should be a priority, and establishing a group for residents, relatives and staff should be encouraged (Owen & Meyer, 2012).

Evidence suggests that many older people in care homes want to be involved in the decisions that affect them (Davies & Brown-Wilson in Meyer, 2007). It is important therefore to improve service user involvement in care decisions and ensure that services are sensitive to the needs of individuals; for example, enabling regular resident meetings to assess both communal and individual needs will enhance participation.

## Food and Nutrition

Research conducted by Torfaen County Borough Council in 2011 highlights the importance of a balanced and nutritious diet. In a case study, the Council states that “paramount to [older people’s] care is the provision of a well-balanced diet, with the nutritional value of the food and overall nutritional balance having a profound effect on their lifestyle and their overall health. Imbalances can cause short and long term damage to their health and well-being” (Smith, Torfaen County Borough Council, 2011).

NICE’s Quality Standard for nutrition support in adults states that malnutrition has a wide-ranging impact on people’s health and wellbeing. Screening for the risk of malnutrition in care settings is important for enabling early and effective interventions. It is important that tools are validated to ensure that screening is as accurate and reliable as possible (NICE, 2012). Malnutrition or ‘under-nutrition’ is acknowledged to be a problem in long term care institutions (West et al 2003, Woo et al 2005, Evans and Crogan 2005) – occurring in two residents out of five in nursing homes and adversely affecting their health and quality of life (Bland, 2005). Other studies indicate that improving the mealtime experience of adults living in residential care ... can be a major factor and a facilitator of improving the care, general health and wellbeing as well as the quality of life of this vulnerable group (Wasielewska, 2012).

## Financial security/autonomy

The concepts of voice, choice and control are fundamental to good quality of life and this extends to having control over personal finances. The literature has indicated that allowing care home residents some financial autonomy helps lessen anxieties about money and helps maintain personal identity and independence (Gabriel & Bowling, 2004).

Crosby et al (2007) recognise the importance of older people's financial autonomy but acknowledge that there will be instances for which assistance is required especially around decision-making. They refer to a potential solution in the form of daily money management (DMM) programmes which assist people who have difficulty managing their personal financial affairs (Crosby et al, 2007). DMM, an idea originating in the US, includes help with simple, routine tasks such as paying bills, preparing cheques for signature, making bank deposits and dispensing cash. It may include more complex tasks such as negotiating with creditors, maintaining home payroll records for employed care staff and calculating taxes. The service is offered by public agencies as well as private, non-profit and for-profit organisations. Individuals who perform the service include accountants, home care workers, bookkeepers, social workers, volunteers, nurses and others (Nerenberg, 2003).

## Privacy

Guidelines published over the past 20 years have emphasised the importance of valuing privacy, dignity, choice, rights, independence and fulfilment. These values underpin the national minimum standards (Department of Health, 2006).

Residents should be able to maintain their privacy at all times, this includes privacy of their personal care, confidentiality of any information owned by or kept about the resident and privacy of their personal space (Grove, 18, 2009). Under the UN Principles for Older Persons, privacy is a fundamental element in maintaining dignity. Dignity is a core human rights principle, and lack of dignity is often at the heart of instances of human rights abuses in health and social care – for example, a lack of dignity is a common theme in examples of abuse and neglect. Closely linked to dignity is privacy. While the two concepts are distinct, privacy can be viewed as an essential aspect of dignity. Other examples include:

- privacy and dignity during personal care, e.g. bathing, undressing
- privacy while using the toilet
- sensitive medical advice being given when other patients can overhear
- care-home residents being fed while on the commode.

Lack of dignity/privacy raises issues under the right to respect for private life and, in more extreme cases, the prohibition on inhuman or degrading treatment (Age UK, 2011).

## Sexuality and Intimacy

“Intimacy and sexuality are basic human needs that are intrinsic to people’s sense of self and wellbeing. Regardless of age, individual’s require companionship, intimacy and love and yet for older people this intrinsic right is often denied, ignored or stigmatised” (Bamford, 2011). The need for human intimacy for most people lasts until the end of their life (Kuhn, 2002).

Many people with dementia, particularly in the later stages, may become less interested in sexual activity. This, however, may not diminish their need for human affection, touch and warmth (Bouman, 2002).

Respecting a person’s individuality and preserving their dignity are the cornerstones of person-centred care. The expression of sexuality and intimacy is fundamental to an individual. Regardless of age, individuals require companionship, intimacy and love and yet for older people this intrinsic right is often denied, ignored or stigmatised (Bamford, 2011).

Weeks (2002) explains that sexual satisfaction is a major contributor to quality of life, ranking at least as highly as spiritual and religious commitment. As Dawne Garrett argues, “we need to recognise that expressions of sexual activity vary considerably among people and that such expressions should not stop when people move home, even if that new home is residential care” (2012).

## External factors affecting QoL

The following issues call for cultural shift and need to be addressed by a range of organisations at all levels of society.

### Staffing – Keeping the workforce fit for purpose

Low pay, low morale, being under-valued and a lack of incentives can and does lead to high staff turnover and a lack of consistent and dependable care. This in itself has a detrimental impact on quality of life and care (Wild, 2010; Bozak, 2003; Ely, 2001).

The changing nature of the workforce in care homes needs to be closely scrutinised through research, in order to ensure quality of life and care for residents. Care assistants comprise the major workforce in care homes but recent research has revealed little is known about the education and training they receive (Royal College of Nursing, 2012). There is evidence that training enhances competence, self-confidence, job satisfaction, morale and teamwork.

A number of areas have been identified as particularly problematic with regard to staffing. These include:

- Staffing levels
- Appropriate skill mix
- Recruitment and retention
- Low levels of morale and extreme pressure at work
- Lack of training

Linked to issues of dignity and staffing, the Promoting Excellence in All Care Homes (PEACH) study focuses on the care home workforce, who “play a pivotal role in promoting the quality of care provided to older people and are therefore a major influence on residents’ quality of life” (Tadd et al, 7, 2011). PEACH works from a set of assumptions that this large workforce “carry out work that is often seen as unattractive, at rates of pay that are seen as under-valuing the contribution made, without a clear career structure, in a sector that is marked by constant change” (Tadd et al, 7, 2011). Combined with other determining factors, such as poor publicity in relation to reports of abuse and the high media profile of cases such as Winterbourne View, the research aims were to:

- Identify positive and negative factors in relation to abuse, neglect and the provision of dignified care
- Explore the views and experiences of the care home workforce about

best practice, training, job satisfaction and wellbeing

- Determine organisational, personal, and practice contexts in which abuse, neglect and lack of respect may occur between staff and residents
- Develop and evaluate an evidence informed training package
- Make recommendations for policy development, training and regulation in care homes (Tadd et al, 2011)

As the report's author explains, "PEACH is distinctive in that it is drawn from detailed observations of daily life in care homes, focuses on enhancing dignity in day-to-day interactions and forms a basis for reflective discussion and peer supervision – an important area for enhancing good practice in care homes" (Tadd et al, 261, 2011).

## Dignity and Respect

Dignity, although difficult to define, is essentially about feelings of personal worth and identity and is necessary for a good quality of life. Both dignity and quality of life are subjective phenomena requiring that service providers understand the values and preferences of the older people they serve (Davies in Nolan, 24, 2006).

In short, there is a need to "know" the resident." Treating residents with dignity and respect is therefore a vital part of residential care and must be ensured in order to maintain a positive culture within a care home and enhance good quality of life. It is also worth emphasising that staff need to be treated with dignity and respect if they are to deliver dignified care to residents. (Tadd et al 2011b, Arino-Blasco et al 2005).

## Communication

Optimising communication between staff and residents will enable a person-centred approach to develop (Moriarty et al, 2010). Open and clear communication between residents/staff/family members should be promoted and a routine feature of care home life especially with regard to residents suffering from sensory loss or dementia and who have different communication needs. Of note here is the work of Susan Kemper and Kristine Williams on the insensitive use of "Elderspeak<sup>4</sup>" by care staff. Elderspeak is a term used to define a means of verbal communication with older people which is at best derogatory and patronising and can significantly undermine

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4 infantilizing communication used by nursing staff

the relationship between carer and resident. Research indicates that there is an increased probability of older people becoming disengaged and disinclined to receive care from staff using elderspeak. Communication training has been shown to reduce elderspeak and may reduce the reluctance on the part of older people to engage with carers. (Williams and Kemper, 2009 & Williams 2004).

## Partnership Working

Some of the literature highlights the need for partnership working to develop new initiatives that give residents, their families and carers greater voice and control (Owen & Meyer, 2012). In particular, healthcare services for older people living in care homes should ideally incorporate multidisciplinary, multi-agency specialist teams. Many localities are developing such services (in England).

Teamwork is another consideration as picked up by PEACH. PEACH research indicates the importance and clear benefits of effective leadership and supervision within the care home in fostering good teamwork and a positive care environment.

## Commissioning, Regulation and Inspection

Care homes are “facing intense scrutiny, local authorities are under financial pressure and national policy is emphasising the importance of personalised care, choice and control. There is growing agreement that care services for older people have to change” (Granville et al, 2014).

The health and social care needs of those living in residential/nursing care are complex and varied. Standard healthcare provision meets their needs poorly, but well-tailored services can make a significant difference (Martin et al, 2011).

The British Geriatrics Society report *Quest for Quality* (2011) describes current NHS support for care homes and makes recommendations as to how care home residents’ quality of care can be improved.

This commissioning guide describes the clinical and service priorities for meeting care home residents’ needs. It details the outcomes needed from commissioned services and suggests how these can be achieved (Martin et al, 2014). The British Geriatrics Society begin by asking the question: why special commissioning for older people in care homes? The answer[s] highlight the distinctness and complexity of need of older people and suggests that approaches to commissioning should be based upon

addressing those needs.

The British Geriatrics Society commissioning guidance focuses on the following areas:

- Health needs
- Access to GP surgeries and outpatient clinics
- Access and advocacy
- Integrated provision
- Managing Disability

Similarly, the Social Care Institute for Excellence (SCIE) has published guidance aimed at addressing failings in commissioning practice, this time with an emphasis placed upon safeguarding issues. The Guide, *Commissioning care homes: common safeguarding challenges (2012)*, aims to identify the issues that commonly lead to safeguarding referrals from care homes (Cass, 2012). The underlying causes are also identified. The Guide includes prevention checklists aimed at helping commissioners and providers to work towards reducing incidences of the main safeguarding issues identified as:

- Maladministration of medication
- Falls
- Pressure sores
- Rough treatment
- Poor nutritional care
- Lack of social inclusion
- Institutionalised care
- Physical abuse between residents
- Financial abuse
- Underlying causes
- Recruitment
- Staffing levels
- Adherence to policy and procedure
- Training
- Choice of service
- Record keeping
- Dehumanisation

The evidence supporting this work was gathered from service users, carers, commissioners, providers, safeguarding leads and the Independent Safeguarding Authority (ISA). “It shows clearly that most safeguarding activity relating to care homes occurs as a result of poor practice and poor quality of service rather than malicious intent” (Cass, 2012). However, it is crucial to

acknowledge that the impact of poor practice and neglect, unintentional as it may be, can be just as significant as intentional abuse and yet it is arguably far easier to prevent.

More recent innovative approaches developed to address the variability of quality in commissioning include the My Home Life Essex scheme. Essex County Council has shifted its commissioning approach from top-down monitoring, inspection and regulation to one that builds relationships, invests in the development of care home staff, and instils a shared vision for care and support for older people (Granville et al, 2014).

### **The Key points of the Essex model are:**

- The 'Essex approach' is based on the social movement My Home Life, which aims to improve quality of life in care homes. A relationship-centred approach focuses on building positive relationships and connections between and among older residents, care home staff and managers, and with commissioners.
- This approach has been embedded in commissioning and procurement of care through a self-assessment process using indicators based on the relational aspects of living in a care home.
- Care home managers are in a pivotal place to model relationship-centred care; where this occurs there are signs staff empowerment and a change in emphasis from task-orientated care to relationship-focused care and support.
- A Leadership Development Programme and facilitated network for care home managers was introduced in Essex, reducing the isolation of care home managers, enabling problem solving with peers and improving the recruitment of care staff.
- Adopting an appreciative enquiry approach that relies on a 'no-blame' culture has enabled staff to build on successes rather than dwell on negatives, and to see everything as a learning opportunity.
- In some homes, adopting a relationship-centred approach and shared decision making with residents has led to care home staff describing a more balanced, creative approach to risk. (Granville, 2014).

The current economic situation however suggests that the future of residential and nursing care will need more than simply a change in legislation to address market sufficiency. The financial fragility of the care home market is a factor that needs to be considered when discussing commissioning. The

KPMG Report, “An uncertain age: Reimagining long term care in the 21st century” (2014), comments on the increasing global demographic of older people and how it will put enormous strain on societies around the world.

Three findings stand out as being relevant to every society; crucially, these are mirrored throughout the literature review:

- Funding is critical.
- Care should be redesigned to break down organisational boundaries through greater integration.
- The discussion should take centre stage and involve government, private and non-governmental bodies and providers, as well as the wider public.

The KPMG report concludes that we have to rethink the way in which long-term care is commissioned and managed and cultural attitudes to ageing need to change, by considering a number of actions including:

- Delivery of person-centred care
- Targeting integrated Care
- Rethinking medical care
- Looking beyond institutional boundaries
- Investing in the formal and informal workforce
- Embracing technology
- Focusing on outcomes
- Developing better funding models
- Carrying out more research
- Changing attitudes and policies towards ageing

Other market analysis reports highlight the following factors that have the potential to negatively impact quality of life and care in residential care settings (Colliers International, 2013):

- Staffing and pay levels
- Running costs
- Care home fees

These factors are particularly significant in Wales (and Northern Ireland) where, “profit as a percentage of income most clearly lag the UK average.” This is in part as a result of high staff costs relative to fee income (Knight Frank, 2013).

## Design and the Architecture of Physical Space

Building design and physical environment make an important contribution to improved quality of life and is referred to in a significant amount of the literature (Parker et al, 2004). Sensitive building design can help develop relationships and a sense of community. It is also important in more practical ways such as access to a choice of communal areas, individual rooms where residents and guests can enjoy privacy and gardens providing safe access to fresh air. Consideration of care home design also provides a continuum of care to minimise disruptive moves (transitions to care). The PEACH study also discusses the theme of design and the feel of a care home emphasising that a care home is “a home” rather than being a place in which one stays.

Work carried out by RNIB also examines improved built environments that enable rather than hinder, producing guidance aimed at supporting organisations and individuals when designing, refurbishing, and maintaining new and existing accommodation and other public spaces. It is based on the principles of providing a fully inclusive environment that supports people with dementia and sight loss to live as independently and safely as possible (John, 2013).

Building design is a critical factor in creating a space fit for purpose for those with sensory loss. Work by the Thomas Pocklington Trust stresses the need for enabling environments; recent research has provided new evidence-based resources that can assist organisations and individuals to create enabling environments that are sensitive to the needs of people with sight loss who also have dementia (Greasley-Adams, 2014).

## Relationship-centred care

Relationship-centred care (RCC) can be defined as care in which all participants appreciate the importance of their relationships with one another. RCC is founded upon 4 principles: (1) that relationships in care ought to include the personhood<sup>5</sup> of the participants, (2) that affect and emotion are important components of these relationships, (3) that all care relationships occur in the context of reciprocal influence, and (4) that the formation and maintenance of genuine relationships in care is morally valuable (Beach, 3, 2006). The roots of relationship-centred care began with the pioneering work of Tom Kitwood, the Bradford Dementia Group and Dawn Brooker. Central to the idea was to see the person not the disease and to create a positive environment of care. The concept has moved forward since its conception and work by Mike Nolan and the ‘Senses Framework,’ has refined

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<sup>5</sup> Kitwood, Tom: Personhood: A standing or a status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition and trust.

relationship-centred care to create an environment in which:

- Staff share a philosophy
- Value holistic care
- Communicate goals to new members
- Involve users/family
- Focus on people not tasks

Crucially, relationship-centred care is about balance; power in care relationships is not one-sided; rather, it is defined by an equilibrium that focuses on involvement and understanding by all parties concerned.

## Information and Advice

Timely and relevant information and advice for residents and their families is vital (Owen & Meyer, 2012). This is reflected in much of the literature (Alzheimer's Society, 2013; Age UK, 2013). Not only is timely information and advice useful, but it can also help minimise anxiety and stress caused by disruption and change (transitions to care). Information should use clear and simple language and be available in a wide range of formats. There should be multiple avenues for providing advice to meet the different needs of older people, including face-to-face advice.

## Challenging Negative Stereotypes

Especially in light of recent scandals involving care homes, there is a need to challenge negative stereotypes about people's perceptions of residential care. Current perceptions of residential care have led to low expectations from residents and family which in turn may support poor care (Bowes, 2011). Older people with high support needs have tended to be missing from debates about 'equality' and 'diversity' (Blood and Bamford, 2010). Older people, especially those living in care homes, are vulnerable to being de-humanised (Bowers, et al., 2009) and the negative stereotype of the 'typical' older care home resident means that society often assumes homogeneity among the oldest generation (Katz et al, 2011).

These expectations need to be increased. It is not enough to be critical of those that fail to address this issue; moreover, it is vital that we give public bodies something to aim for and that we play a role in driving forward positive change. Equally, there is a need to challenge negative stereotypes of older people. For care home staff, person-centred and relationship-centred care is important here as it goes a long way to debunking myths surrounding these negative stereotypes and assumptions that the needs of all older people are the same.

## End of Life Care (EoLC)

Although outside the Commissioner's Terms of reference, this is an issue referred to in a fair amount of the literature (also referred to as quality of death) and was one of Tom Owen's best practice themes in My Home Life. Nursing and residential care homes play an important role in the care of older people at the end of life. Together, they provide final care for 16% of the population, rising to 30% of those aged over 85. Encouraging and facilitating an open approach to the awareness of dying is a key theme within the literature (Katz, 2001, 2003a, 2003b, 2004, Nolan et al, 2003, Froggatt, 2001, Moriarty et al 2012, Percival, 2013, ) and in policy, e.g. the National Service Framework for Older People (DH, 2001). The PEACH study also found that this was an area of knowledge which care staff felt they were poorly prepared for.

## Transitions to Care

Transitional care is a set of actions designed to ensure coordination and continuity of care. It should be based on a comprehensive care plan and the availability of well-trained practitioners who have current information about the patient's treatment goals, preferences, and health or clinical status. It includes logistical arrangements and education of patient and family, as well as coordination among the health professionals involved in the transition (American Medical Directors Association). From a system perspective, a safe transition from a hospital to the community or a nursing home requires care that centres on the patient and transcends organisational boundaries (Jencks et al, 2009). The upheaval of moving to a care home can be very stressful for older people, their families and their carers; good quality of life can however be achieved with effective planning and support (Owen & Meyer, 2012). The provision of timely and useful information is essential here and allows the older person to be proactive in decisions about their future.

## Use of Technology

In addition to the use of standard technologies already utilised by care homes (aids and adaptive technologies) there is a growing need to introduce and promote the use of more non-traditional technologies that will allow residents to engage and participate more fully (Turpin, 2012). "So many older people in care homes do not live close to their families. Adopting technology is an obvious solution to provide a 'window on the world'. Social isolation is a significant issue for older people and it is easy to see the connection between the 'social' in social networks and the potential to combat loneliness" (Ayres, 2013). Research carried out by Digital Unite into the use of the internet by

over 55s found that:

- four out of five (86%) reported that the internet had improved their lives
- 72% said being online had helped reduce their feelings of isolation
- 81% said using the internet makes them feel part of modern society (Ayres, 2013)

Technology may benefit older people so that they might:

- gain new and extend existing knowledge;
- learn about using new technologies and gain confidence and competence in doing this;
- gain skills for communication;
- increase their self-expression; and
- help overcome the communications gap (March, 2010)

## Areas for review that impact on QoL

- **Interaction:** Promote and encourage -- maintaining existing friendships as well as developing supportive friendships with other residents is important for residents and should be encouraged.
- **Independence:** The freedom to exercise voice, choice and control is fundamental to maintaining independence in residential care. Care providers must legally respect the basic rights and freedoms contained in the European Convention on Human Rights, which is covered in the UK by the Human Rights Act 1998. Such human rights include rights to privacy, dignity, independence, security, civil rights, fulfilment, respect for diversity and equality (Hodgson, 2013). Particular emphasis should be placed on recognising the need for and promoting individual autonomy, especially given that many of those living in residential care will lack this.
- **Daily Activities:** Staff and family members should be encouraged to recognise the value of one-to-one and group activities. Expert advice on suitable activities should be available in every care home.
- **Participation:** Unless contrary to the wishes of residents and/or their families, staff should be encouraged to consider residents (and their families) as “expert partners in care.”
- **Relationships:** Staff should seek to understand each individual resident’s priorities for quality of life and address the key influences on this, such as the environment, meaningful activities and relationships, both through the care they offer and everyday life in the home.
- **Dignity:** Renewed emphasis needs to be placed on the way in which older people are treated in care settings, ensuring their dignity. There is a great deal of evidence that dignity and lack of it impacts greatly on quality of life; the lack of dignity leads to humiliation (Foster, 2011).
- **Community:** Closer working links with local communities, colleges and the care-home sector should be promoted and encouraged. Care home policies should be ‘user’- and ‘family’-friendly (SCIE, 2007); moreover, engaging with family and community members should be encouraged. Close links with the local community should be maintained.
- **Staffing:** Recruitment and retention of care-home staff is a major issue (RCN, 2012); training and qualifications are important areas in need of address in part to encourage and attract people to the sector and to provide incentives and motivation. Care homes should provide good

learning environments for staff and students (My Home Life Cymru) in order to develop the necessary knowledge and skills. PEACH developed a training programme and devotes much attention to this aspect of care homes. A number of studies over the last decade have identified “a renewed interest within the academic research community in the need for on-going education, training and support for the social care workforce, possibly in response to the growing importance of the care home sector as the U.K. age demographic changes” (Tadd, 2011a). Training has a key role to play in improving the quality of care experienced by those who live in care homes.

- **Physical Health:** The availability of and access to high quality healthcare is a basic human right, anything less than this is unacceptable. Localities should strive to re-establish multidisciplinary and multi-agency healthcare support for older people in long-term care.
- **Care Planning:** Shared decision-making in relation to an individual resident’s plan of care requires regular, planned reviews involving the home manager, named nurse, key-worker, resident and family members (Kina, 1996).
- **Medication:** There is a clear need for better management of medication in nursing homes (Szczepura et al, 2008). Appropriateness of drug use is an important indicator of the quality of care. It is unclear how the literature on nursing homes relates to residential care.
- **Communication:** Communication and information sharing should be encouraged as this can allow all stakeholders to be involved in decision-making processes as well as helping minimise anxiety.
- **Integration/partnership:** Better integration of services for older people has long been promoted as improving quality of care and potentially reducing costs (Szczepura et al, 2008).
- **Care Home Design:** Care home design/planning should consider layouts that effectively supports and promotes relationship building such as access to a choice of communal areas in close proximity to each other and close to staff areas.
- **Identity:** Maintaining identity is a vital part of providing dignified care and links with self-esteem and individual perceptions of quality of life, it is thus an important area to explore in care-home settings. Moving to and living in a care home can serve to undermine one’s identity or sense of self in a number of ways.

- **Decision-making:** All residents, their families and staff members should be provided the opportunity to be involved in decision-making processes that affect them. A culture of open communication and information sharing needs to be encouraged enabling all stakeholders to be involved in decision-making processes.
- **Support:** The development of cultures that support relationship-centred care is to be encouraged. Through publications, organisations, groups and networks, existing initiatives that support the development of cultures supporting relationship-centred care should be shared and disseminated.
- **Relationship-centred care:** The development of cultures that support relationship-centred care should be explored. Through publications, organisations, groups and networks, existing initiatives that support the development of cultures supporting relationship-centred care should be shared and disseminated.
- **Consultation/Complaints:** Residents and their families should, without fear of repercussion, be given the opportunity to air their concerns and anxieties at the time of admission and at regular intervals.
- **Information and Advice:** Increase the provision of information in various languages, styles and formats ensuring residents and family members are given access to up-to-date and relevant information and advice
- **Food and Nutrition:** As well as ensuring that residents' diets meet their nutritional needs, it is equally important to give residents choice and control in what, when, and where they eat.
- **Quality improvement initiatives:** Quality improvement is more likely to be successful in homes with a culture that promotes innovation and staff empowerment (Szczepura et al, 2008).
- **Sensitivity:** Whilst general care should be of a high standard, service providers should be sensitive enough to allow for individual variation and ensure a degree of specificity with regard to disparate groups of people who receive or provide care (or both)
- **Stereotyping:** All stakeholders, including service providers and regulators, staff, older people and their advocates could consider how they can share good practice and how they might promote living in a care home as a positive choice for housing and care – for example, through publications

- **Transitions into Care:** Transitions to care homes and factors influencing the choice of residential care over alternatives are critical. The pressure of transition can be eased if the older person is permitted to play a full role in the planning/decision-making process. This also works for the older person's family who could be permitted to work with staff in the care of the older person.
- **Sexuality/Intimacy:** Care home staff should encourage residents to cultivate friendships and interact with each other, while continuing to monitor in order to ensure that this is in the best interests of those involved (Bamford, 2011).

# Dementia

## Key Facts:

- In 2013 there were an estimated 45,529 people living with dementia in Wales (Ageing Well in Wales, 2014)
- Of these only 17,661 have received formal diagnosis (Ageing Well in Wales, 2014)
- By 2021 it is estimate that over 55,000 people in Wales will have dementia. (Ageing Well in Wales, 2014)
- Two thirds of older people in residential care have dementia<sup>6</sup>.
- Dementia occurs in 5% of people over 65 years old, rising to 30% of people over 90 years old (Hofman et al, 1991).

Surprisingly little is known about the quality of life of those with dementia living in residential care settings (Macdonald et al, 2002). While the majority of people with dementia live in the community, one-third of people with dementia live in care homes. It is estimated that at least 80% of people in care homes have dementia or significant memory problems. This means that dementia is core business for care homes; it is essential that they are able to provide services which meet the desired outcomes of people with dementia (Kane, Alzheimer's Society, 2013).

The Alzheimer's Society report, Dementia 2013: The hidden voice of loneliness, reveals that more than two-thirds (70%) of the UK public said they would feel scared about moving into a care home in future. This is in large part due to recent high-profile scandals relating to residential care; however, cases of undignified treatment, while unacceptable, are not the norm (Kane, Alzheimer's Society, 2013). The same report also found that:

- Nearly three quarters (74%) of carers would recommend the care home the person with dementia was in
- Over two-thirds (68%) said the quality of care in the home was good; however:
- Less than half (41%) of carers thought that the quality of life of the person with dementia living in the care home was good. This suggests more work is needed to promote and improve quality of life of people

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<sup>6</sup> Alzheimer's Society, written evidence to Health and Social Care Committee Inquiry into residential care RC50, p2

with dementia in care homes (Alzheimer’s Society, 2013).

The Welsh Government’s National Dementia Vision for Wales outlines four key priorities underpinned by four action plans to help people live well with dementia. These include actions to improve the quality of dementia care within care homes. There has been no formal evaluation of how successful the Dementia Vision has been but there is considerable evidence that training and understanding about dementia is not sufficiently prioritised within the care home sector.

Indeed, evidence given to the Health and Social Care Committee inquiry into residential care states that “training in the care of older people with specific health needs such as ... dementia is considered less than adequate in the sector and is an issue of concern given the increasing prevalence of these conditions<sup>7</sup>.” The document also goes on to state that the Royal College of Psychiatrists in Wales recommended that all care homes should have mandatory training in dementia care. Julie Jones from SCIE told the Committee that:

“All care homes need sufficient knowledge and experience to manage dementia care well. That is also true of people in healthcare settings and of acute hospitals. The prevalence of dementia in our older population as it currently stands means that anybody in those front-line jobs has a responsibility to know what good dementia care looks like and we need to make that easier for front-line staff and their managers.<sup>8</sup>”

The PEACH study found that staff in care homes lacked skills in caring for people with dementia and understanding their needs. Their research revealed that it isn’t just training in dementia care that is required; it is the correct type of training that is often lacking.

In a study to identify the unmet needs of people with dementia in care homes, Geraldine Hancock (et al) assessed 238 residents using the Camberwell Assessment of Needs for the Elderly (CANE) tool (Appendix 2). Hancock found that the environmental and physical needs of residents with dementia were usually met. “The most common unmet needs were for daytime activities, sensory problems, psycho-logical distress, memory problems and lack of company” (Hancock et al, 48, 2006).

Although unmet needs were not related to either the severity of dementia or the level of the resident’s dependency, they were associated with

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<sup>7</sup> National Assembly for Wales, Health and Social Care Committee, Consultation response RC65 – Cymorth Cymru p6 [accessed 19 October 2012]

<sup>8</sup> *ibid*

psychological problems, such as anxiety and depression. The authors conclude that mental health services and residential-home staff need to be aware that many needs remain unmet and that much can be done to improve the quality of life for residents with dementia.

The literature specific to those with dementia in residential care list the following key areas as promoting quality of life and care:

- Family
- Intimacy
- Relationships (with other residents and outsiders)
- Keeping active/feeling useful/meaningful activities
- Religion and spirituality
- Staff and interactions with staff

The literature also highlights some of the difficulties in assessing quality of life in dementia:

- Memory problems may lead to problems in generating accurate self-assessment
- Problems with maintaining attention may make it difficult for a person with dementia to focus on the interview
- Language disorders, which often feature in dementia, can limit the scope for full participation in discussion
- Lack of insight may mean some people with dementia are unaware of their impairments or deny or minimise them
- The capacity to make judgements can be impaired in people with dementia, making it difficult to produce a valid judgement about quality of life
- Accurate self-assessment may also be compromised by challenging behaviour such as agitation or anxiety
- The progressive nature of dementia means that the nature of quality of life, and therefore the means to assess it, is likely to vary over time (Smith, 2005)

A number of studies linked to dementia and residential care have been funded by the Prevention of Abuse and Neglect in the Institutional Care of Older Adults (PANICOA), some of which will be discussed in this section and throughout this review. PANICOA funds a number of separate, but linked,

studies utilising a range of perspectives and methods.

One such piece of research was headed by Professor Dawn Brooker and has resulted in the development of an observation process called PIECE-dem (Person Interaction Environment Care Experience in Dementia) the purpose of which is to capture the experiences of those living in residential care with advanced stage dementia and high-level needs; in short, those who are most likely to experience a poor quality of life. Further development of the process is intended which will include adapting it for use by practitioners to assist in gauging the experiences of the most vulnerable residents.

Key to accurate assessment and improved care is “knowing” the person with dementia. Brooker emphasises the importance of person-centred care for people with dementia. She argues that person-centred care is not a single thing or intervention; it is a set of guiding principles for our actions in the field of dementia care that enable people with dementia to be in relationship with others.

Led by Brooker, the Association for Dementia Studies at the University of Worcester has developed what is known as the VIPS Framework:

- **Values** – recognise the value of all human life regardless of age or ability
- **Individuals** – focussed on each unique person
- **Perspective** – looking through the eyes of the person needing care
- **Social** – seeing and responding to a person rather than a unit of care (Brooker, 2007)

The Care Fit for the VIPS toolkit has been designed to help:

1. Decide how well a care home is delivering care at present and identify priorities for improvement
2. Find useful information and resources on person-centred dementia care
3. Record, plan and test ideas for improvement (Brooker, 2007)

Brooker states that it is vital that health and social care staff should be able to help people with dementia make decisions, cope with feelings, manage their relationships with others and maintain their independence for as long as possible. Furthermore, Brooker argues that the person-centred approach is vital as it places the person, rather than the illness, at the centre of care. In contrast, the medicalisation of dementia with a focus on illness, has carers

and the people who experience dementia reporting that the person inside is lost or ignored.

Brooker concludes that a person-centred approach requires an organisational culture change; leaders and teams need to value staff and each other. In order to check how person centred they are, care home staff should ask themselves:

- Do my actions value and honour people living with dementia? (and staff in my staff team)
- Do I recognise the individual uniqueness of the people I work with?
- Do I make a serious attempt to see my actions from their perspective or stand point?
- Do my actions provide the support for people with dementia to feel socially confident and that they are not alone? (Brooker, 2007)

Care homes and other care settings can sign up to a Dementia Pledge in keeping with a person-centred approach. The pledge is made up of a set of principles designed to promote and maintain positive, person-centred care for those with dementia.

Brooker has also been a key figure in Care Home Organisations Implementing Cultures for Excellence (CHOICE), another PANICOA funded initiative. The aim of CHOICE Project is to examine the links between organisational cultures and the care experiences of older people living in residential and nursing care.

The Association for Dementia Studies has been working in “partnership with the University of East Anglia, University of Stirling and Cardiff University to carry out 12 in-depth case studies of care homes across the UK, analysing positive and negative care experiences of older people in long term care in relation to the contexts, cultures and factors that positively or negatively predispose to their occurrence” (Brooker et al, 2014).

A key aspect of this work recognises the negative impact the media can have on the good work carried out by care home staff. Most often, reports of mistreatment overshadow the good work that is done.

The study aims to add to existing knowledge about the “role of organisational culture in ensuring good care and how changes could be made where there are particular risks of poor care” (Brooker et al, 2014). The final outcomes should provide a framework, or benchmark for “all those involved in providing

and regulating care homes and for families and potential residents purchasing care” (Brooker et al, 2014).

Professor Bob Woods’ recent work has focused on the importance of family involvement in care homes for people with dementia. Woods states that, “we now appreciate that guilt feelings and strain may be strong at any stage of the care-giving journey, and that the admission to a care home does not signal the end of the ‘care-giving career’, just a change in responsibilities. We also know that residents’ quality of life tends to be higher in homes where family involvement is higher” (Woods, 2010).

Woods concludes by saying that “It is encouraging to now see more homes taking up an approach which values the input of families, and does not see them as ‘problems’. Nothing can remove the pain of losing a loved one to dementia, but supportive and understanding staff can make a real difference to the experience” (Woods, 2010).

David Sheard, Chief Executive and founder of Dementia Care Matters, is known for his pioneering work in dementia care around “mattering” and person-centred approaches. Sheard argues that:

- Mattering is feeling deep inside that to someone or something and somewhere you really count
- Mattering is about knowing that just being who you are really matters
- Mattering is having evidence you can see, hear and feel that you make a difference and are needed
- We need more “being” person centred and less “doing” person-centred
- Dementia care needs to be heartfelt, not soulless and meaningless care designed to attract maximum income
- Dementia Care Matters studied 100 observational qualitative audits that revealed that 70% of people spend their time experiencing boredom and lethargy
- This boredom is made worse by environment of “controlling” Care with strong “them” and “us” culture
- We need more people who love and care for us, not just do things for and to us

Dementia Care Matters has a 50 point checklist<sup>9</sup> that care homes can use to measure the quality of their dementia care that includes the following headings:

- Removal of Us & Them Barriers leading to Culture Change
- Feelings Matter Most
- Evidence of physical and Emotional Freedom
- Focusing on the Mealtime Experience
- Create meaningful ways to occupy
- Evidence of a dementia specific environment

Crucially, the Alzheimer's Society 2010 literature review for the **My name is not dementia** report identifies the challenges of involving people with dementia from seldom heard groups such as:

- BME groups
- People in rural settings
- People with learning disabilities
- LGB&T

The literature review also explores a number of other important issues with reference to dementia and cognitive impairment that includes:

- Language and terminology used
- Methods of communication
- Involvement of carers
- Applicability of the concept of recovery and rehabilitation
- The separation of dementia services from mainstream mental health services (Warner et al, 2010)

Importantly, the main issues emphasised in the bulk of the literature are not disease-orientated (Byrne-Davis et al, 2006) but are issues that could conceivably be generated by many different groups of people:

- Social interaction
- Psychological well-being
- Church/god/religion/spirituality
- Independence
- Financial security
- Health

Significantly, this evidence suggests that the domains of quality of life highlighted as important by people with dementia are similar, or even the same, as those emphasised by people without dementia.

<sup>9</sup> Retrieved from: <http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0COC0QFjAA&url=http%3A%2F>

## Review Preparations

- **Research preparations** - OPCW Staff should receive training in a methodology that enables the QoL of residents with dementia to be captured.

## Review outcomes for consideration

- **Awareness and Understanding:** Care staff should be aware that many needs of those with dementia remain unmet and that much can be done to improve the quality of life for residents with dementia.
- **Communication:** Greater awareness of the use of language and terminology is needed and a general improvement in methods of communication.
- **Training:** Education and specialised training in the care of people with dementia is needed.
- **EoLC:** Care home staff often lack the training and confidence needed to support people with dementia at the end of life (SCIE, 2012). Experiential learning to help them see the world from the resident's perspective can be valuable.

## Administering medication

As a recent Centre for Policy on Ageing (CPA) report highlights, “most older people in care homes are taking several medications and errors may arise at the point of prescribing, dispensing, administering or monitoring that medication. Recent research has highlighted the unacceptably high levels of medication error” (CPA, 4, 2012).

A report published in conjunction with the Safety of Medicines in the Care Home project provides a series of recommendations aimed at addressing the main obstacles to the provision of safer administering systems. The partnership project, funded by the Department of Health, aims to improve the medicines pathway for residents in care homes.

The partnership, led by the National Care Forum (on behalf of the Care Provider Alliance) was formed to try and address some of the issues raised by the Care homes’ use of medicines study (CHUMS) report.

The main findings of the CHUMS report:

- Residents (mean age 85 years) were taking an average of eight medicines each.
- On any one day seven out of 10 patients experienced at least one medication error
- Homes could be working with between 1-14 different GPs (mean 3.8/home) and between 1-4 different pharmacies (mean 1.5/home)
- Whilst the mean score for potential harm was relatively low, the results did indicate opportunity for more serious harm (National Care Forum, 2013).

The CHUMS report identified the following key issues:

- Overprescribing for older people
- Medication review and lack of monitoring
- Person centred approach to care planning
- Out of hours support for care staff
- Transfer of care
- Use of homely remedies
- Use of monitored dosage system (MDS)
- The need for better systems for communication
- Use of technology
- Improved training and development

- The availability of practical tools to support care staff
- Leadership – the role of the care home manager/lead nurse

# The Literature relating to Protected Characteristics

## Lesbian, Gay, Bisexual (LGB)

The literature relating to LGB issues is in short supply. Although the topic makes up 6% of the literature assessed in this review, LGB issues were specifically targeted during the research phase, meaning that 6% is not an accurate reflection of the overall literature relating to quality of life in residential care. It should also be pointed out that no transgender literature relating to residential/nursing care was sourced during the course of this review hence the exclusion of the term “trans” in the heading. However, figures suggest that there is a pressing need for more work to be carried out in this field:

- The older LGB population of the UK - estimates vary from 2-10 per cent (Aspinall, 2009)
- Estimates suggest that the entire LGB population of the UK may be up to 1.2 million (Office for National Statistics, 2005)
- In a study conducted by the Commission for Social Care Inspection (CSCI - 2008); only 7 per cent of care homes reported carrying out specific work around equality for LGB people and less than 1 per cent of care homes had done any specific work around sexual orientation and assessment or care planning.
- Dementia/LGB – By extrapolating out the figures provided by Aspinall regarding those living with dementia in the UK, a range of 21,000 (2 per cent lower estimate) and 63,000 (6 per cent common estimate) LGB people may be represented in these figures.

A key point revealed in the limited research that does exist suggests that older LGB people may have a greater need for health and social care services because, compared with their heterosexual contemporaries, they are:

- Two-and-a-half times as likely to live alone
- Twice as likely to be single; and
- Four-and-a-half times as likely to have no children to call upon in times of need (Knocker, 2006)

- 36% of LGB people (aged 60–91) had been subjected to verbal abuse. (Knocker, 2006)
- 44% of men and 16% of women had been physically attacked (gay and bisexual men were three times more likely than lesbian and bisexual women to be physically attacked) Lower self-esteem and increased thoughts of suicide were associated with experiences of violence (Ward et al, 2010)
- Only 25% of older LGB people believed that health professionals were positive towards LGB people. (Ward et al, 2010)
- Only 16% trusted health professionals to be knowledgeable about LGB lifestyles (Heaphy, 2003)

Despite issues relating to LGB groups forming a relatively small part of the literature, what does exist is quite thorough, the key aims being to:

- Identify how the sexual identities and relationships of older LGB residents are supported by:
  - care and nursing staff in care environments;
  - agency management; and,
  - policy at provider and national levels
- Identify how the sexual identities and relationships of older LGB residents are supported by:
  - care and nursing staff in care environments;
  - agency management; and,
  - policy at provider and national levels
- Identify the hopes, expectations and concerns of LGB adults (50+) about residential care services (Willis, 2013).

With regard to LGB issues, Dr Paul Willis' report, Provision of inclusive and anti-discriminatory services to older lesbian, gay and bisexual-identifying (LGB) people in residential care environments in Wales, recognises that sexuality and sexual health are crucial to older people's health and wellbeing.

Older people are often assumed to be asexual (Bauer, Nay & McAuliffe, 2009) or heterosexual and that older people who identify as LGB can experience "dual discrimination through the heterosexist assumptions of care

providers and through ageist beliefs circulating in local communities” (Clarke et al, 2010). UK literature about older LGB people’s experiences in care environments is identified as “very lacking;” this also applies to recognition by staff and regulatory bodies (such as CSSIW) of the care needs of LGB people in Wales. Willis’ report addresses this gap by examining the current level of inclusive care being provided by care environments to older LGB people in Wales. Crucially, Willis asks: How are the sexual identities and relationships of older LGB residents perceived and supported in residential care environments in Wales?

Willis’ paper culminates in a series of recommendations aimed at various bodies. Here he states that:

**CSSIW needs to:**

- Lead in reporting on care environments’ capacity to provide and inclusive, anti-homophobic environment for LGB older people.
- Introduce explicit statements into the National Minimum Standards for Care Homes for Older People.

**Providers need to:**

- Enhance positive recognition of older LGB people within care setting by:
  - Addressing sexual orientation at planning and assessment stage
  - Implementing equality policies
  - Including LGB people in statement of purpose
  - Displaying visual signs of positive recognition
  - Developing measures to redress organisation cultures
- Introduce and deliver proactive training to:
  - Raise awareness of LGB histories/discrimination
  - Share strategies for challenging homophobic views
  - Provide evidence based knowledge about sexual functioning, relationships and the rights of older people

**Researchers and policy makers need to:**

- Articulate more concrete actions on how services will be supported and resourced to ensure care and nursing staff are actively including older LGB people in their practice (this is based upon Dr Willis’ point that LGB people are not a homogenous group, but have individual needs that require further recognition by service providers).

- Dr Willis acknowledges the gap in the report regarding gender identity and gender re-assignment, he therefore suggests that future researchers ensure that the voices of people receiving care services are included. He suggests that this will provide evidence as to whether current UK and Welsh law and social care policy is being translated into practice.

## Review preparations

**OPCW research preparations:** Ensure representation of LGB and T groups in focus groups and the Commissioner's Welsh Language and Equalities Advisory Board.

## Review considerations:

- **Staff Behaviour:** care home staff should consider the type of humour/ language they use and to guard against patronising behaviour, smiles, salacious remarks or laughing at the residents
- **Internal Policy:** Equal opportunities policy should be put into practice to ensure that facilities are available to all, regardless of disability (including dementia), sex, gender identity, age, sexual orientation, marital or parental status or HIV status
- **Education:** Management and care home staff should encourage, promote and educate other residents whose misconceptions and prejudices may be interfering with another resident's right to express their sexual identity considering how work is allocated, as far as possible, to meet an individual resident's preferences for sexuality and gender of carer.
- **Strategies:** In situations where a resident's behaviour is particularly challenging, staff preferences may also need to be considered using sensitive strategies to address overtly 'inappropriate' behaviour encouraging open discussion among staff and residents to ensure that residents' sexual needs can be accommodated rather than ignored. (Heymanson 2003, Springfield 2002, Hurlley 2005).
- **Positive Culture:** Providers should enhance positive recognition of older LGB people within care setting.

## Black and Minority Ethnic (BME) groups

Little is known of the experiences of BME older people in care homes (Bowes, 2011). Although the theme makes up 6% of the literature reviewed in this paper, BME issues were specifically targeted during the research phase, meaning that 6% is not truly representative of the total literature relating to quality of life in residential care.

The fact that little is known of BME experiences may formerly have been due to the younger age profile of some BME groups in the UK, or to traditions of caring for older people within families (Bowes, 2011). However, the BME population is now ageing rapidly (Lievesley, 2010) and there is evidence that, despite deep rooted traditions of family care in many communities (Ahmad, et al 1996), residential care is increasingly an option for frail older people, particularly those without family support.

Despite the shortfall in the volume of research being conducted in this specific area, what does exist is quite detailed. Alison Bowes, for example, identifies the “potential for mistreatment of BME older people in care homes if care is not culturally competent and if unintentional or intentional racism may occur” (Bowes, 5, 2011). The report focuses specifically on dignity and respect. There are 4 central themes that emerge from her research and these appear to correspond in terms of the general literature relating to BME issues:

- Relationships of care
- Culture and religion
- Mistreatment
- Dignity and respect (Bowes, 2011)

Likewise, Freda Mold’s article, Minority ethnic elders in care homes, finds that the “heterogeneity of the population highlights the need to offer a range of services that reflect people’s language, cultural and religious differences” (Mold, 107, 2005). The review assesses the literature concerned with minority ethnic elders in care homes. It has been classified into two key areas:

- Issues arising from international literature, including factors relating to access, equality and workforce issues, care satisfaction and placement decision-making.
- Issues emerging from the UK literature. Issues of particular concern include barriers to care provision for minority ethnic older people, loss of independence and the recognition of cultural needs (Mold, 107, 2005)

The literature review also highlights the absence of studies focusing on the perception of care from residents' perspectives and their involvement in making placement and care decisions. Evidence suggests that in providing care to ethnic older people it is essential to acknowledge:

- Residents' general background
- Lifestyle
- Religious and health beliefs and practices
- Language preference

Acknowledging ethnic diversity is "critical since for many ethnic elders, ethnic heritage, culture, religion, customs and rituals are firmly embedded in an individual's usual living arrangements" (Verhoeff, 5, 2011). This idea is reaffirmed in Judith Phillips' *Care: Key Concepts* in which she argues for more diverse thinking around the concept and states that "the concept of care is shaped by our cultural values... Most of the debates surrounding care have been in developed Western countries and therefore the concept of care is primarily discussed throughout from white, ethno-centric perspectives... yet care is a notion that also needs to be debated at tribal and local community levels" (Phillips, 2007).

Citing Mold's research, Owen's *My Home Life* report recognises individual cultural need and provides a list of distinct needs of minority ethnic older people in care homes (see Appendix 3).

The literature (predominantly international according to Mold) identifies the following key themes:

- Access and equality issues
- The multi-ethnic environment and workforce issues
- Identity, care satisfaction and placement decision-making (Mold, 2005)

Key themes to emerge from the UK literature:

- Barriers to care provision for minority ethnic older people
- Independence and cultural needs (Mold, 2005)

Key points to emerge from the literature review:

- International studies indicate possible differences in the preferences of care to minority ethnic elders, especially in relation to the nature of their care and their participation in care decisions
- UK literature specific to the care home sector is limited (Mold, 2005)

- Existing literature highlights the need for greater cultural awareness, including communication issues in order to enhance individualised care
- There is a lack of UK research exploring the needs of minority ethnic elders in UK care homes
- Until further research is conducted we will continue to know very little about the needs of minority ethnic elders in care homes (Mold, 2005)

## Review preparations

**OPCW research preparations:** Ensure representation of BME groups in focus groups and Welsh Language and Equalities Advisory Board.

### Considerations for the Commissioner's review:

- **Staffing:** Providers should encourage and promote recruitment of staff from different ethnic groups so that workforce reflects local population. However, it should be noted that research on recruitment to the care sector suggests that this is unrealistic.
- **Training:** Care homes should provide staff with culturally competent care training. This should include promoting cultural sensitivity and educating staff in aspects of cultural/ethnic diversity and responding to racism. Valued attention to cultural preference avoiding assumptions through stereotyping is key.
- **Language:** Care homes should have (and provide) ready access to translation and interpretation services and consider the option of hiring staff able to converse in a language prevalent at a particular home.
- **Food:** Care homes should be sensitive to, have an awareness of, and give consideration to the provision of culturally and ethnically specific foods as and when required.
- **Design:** Planners/providers should consider aspects of building design (that take into account needs of particular groups). This may include washing and toilet facilities; potential for segregation of male and female quarters; areas for prayer and meditation; and/or requirements relating to food storage, preparation and cooking.
- **Managing relationships:** can prevent mistreatment, neglect and abuse - mutual respect between staff and residents and between residents is essential.

- **Communication:** Good communication beyond linguistic capacities, is essential.
- **Complaints:** BME residents and family are traditionally inhibited from complaining about poor care because of negative experiences. It is essential staff understand this and ensure that residents/family feel safe in raising concerns.
- **Expectations:** Low expectations from residents and family may support poor care. These expectations need to be increased.
- **Recognition and Support:** The needs of, and challenges, faced by multicultural staff require recognition and support.
- **Rights:** Recognition of the residents' rights to enjoy a full life is essential by staff – sharing of good practice and better training is required.
- **Dignity and Respect:** Good relationships are founded on dignity and mutual respect – work in multicultural contexts requires great skill and should be recognised and rewarded.
- **Transitions to care:** The quality of care must be judged from the perspective of the resident and their involvement in placement and care decisions must be a part of the process.

## Spiritual/Religious (including a lack of religious belief)

Although referenced earlier in this literature review, little research pertaining to spiritual or religious needs and care homes has been found. There is also a marked lack of distinction between spirituality and religious faith with references to spirituality mainly affiliated with religious beliefs. There is however increasing recognition that spirituality may not be the same as following a religious faith, although for some people this is their path. Indeed, spirituality is increasingly being seen as the individual's search for meaning in his or her life. Therefore, meeting spiritual needs can encompass activities such as reading, expressive arts, music, walking and gardening, given that all these activities provide opportunities for creative meaning, gaining a sense of control, experiencing/expressing joy and nourishing the soul (Rose 1999 cited in Johnston and Mayers 2005).

Patricia Higgins notes that despite a series of studies showing that older people are reported to be a highly spiritual and religious group, the spiritual dimension, as an essential component of holistic care, is frequently overlooked in the literature (Higgins, 2011).

Despite a shortfall in the overall amount of literature relating to these issues, what does exist is quite detailed. For example, Khalid Saud Alshareef's presents a case study of the role of Islam in nursing homes in Saudi Arabia and identifies religion as a significant coping resource.

Alshareef's doctoral research demonstrates the positive influence of religion on transitional periods in later life, specifically looking at the adjustments that have to be made when entering a nursing/care home. His study shows that religion serves as stabilising influence on older men's lives, providing a level of spiritual consistency, direction and support.

To this end, the study found that religion was an important dimension in everyday life. The study highlights the need to acknowledge the importance of religion in the social care provision for older people in Saudi Arabia, for example, in counselling, in social work provision in general and within residential homes for older men in particular.

The Leveson Centre carries out work specifically relating to older people and religious faith and spirituality and is a good source of research information. The Centre's aims include developing an understanding of spirituality as lived by older people. In all its work, the Leveson Centre tries to make tangible links between policy and practice and tries to support and enable older people to influence policy makers, professionals, carers and churches.

Oliver Valins work, through the Leveson Centre, looks at the care of older Jews in the UK. He identifies the older Jewish experience as key in identifying future trends and care needs in the UK and sees the Jewish historical approach to ageing and the specialist needs of older Jewish residents in long-term care as a "bellwether for other minority and faith groups and indeed for society more widely (Valins, 2010). Valins states that "British Jews are where the rest of society will be in the next 10-20 years," adding that British Jews are "Demographic pioneers." The rationale for this stems in part from the statistical evidence:

- Some 16 per cent of the UK population is aged 65 or over, whereas one quarter of UK Jews are in this age cohort.
- The proportion of Jews aged 75 and over is twice that of the UK as a whole (14 per cent as compared to 7 per cent).
- Jewish women have a life expectancy that is two years longer than the UK average, and for men the figure is four years.

The care of the older Jewish community in the UK is firmly rooted in cultural

and religious tradition in which older people are an integral and valued part of society. Valins notes the importance and significance of the UK Jewish voluntary sector which provides, as Valins puts it, a “shadow network that runs parallel to state, private and wider voluntary sector provision” (Valins, 2010) .

Indeed, the Jewish voluntary sector is vital in sustaining and supporting the care of older Jews in the UK. Valins states that “altogether there are almost 2,000 financially independent organisations within the Jewish voluntary sector (which includes organisations ranging from educational charities to Zionist groups, representative bodies to sheltered housing agencies), and these have a combined annual income of £500 million” (Valins, 2010). Included within this voluntary sector is a network of 36 care homes that cater for two and a half thousand older Jews.

This voluntary network provides the kind of support lacking in other areas of British society and Valins’ concludes with a warning of sorts: “for other ethnic and minority faith communities, the lessons are perhaps more daunting. These communities are likely to experience the same demographic effects of an aging population in the coming years and will need to provide care services that are capable of meeting the needs of their older people. To do so without the capital and experience infrastructure that the Jewish community possesses is going to be extremely difficult” (Valins, 2010).

Although there is not a great deal of literature relating specifically to spirituality and care homes, there is a fair amount of research relating to spirituality and ageing. For example, Mowat and O’Neill’s, *Spirituality and ageing: implications for the care and support of older people* examines the meaning of spirituality and its importance in older age.

Although the definition of spirituality is contentious, it is generally perceived as a search for meaning. “For some people, divine presence is central; for others, spirituality is a secular concept involving inner life, personal belief and focusing on self” (Mowat & O’Neill, 2013). In the context of care, the following, provides a more satisfactory and universal definition:

“Spiritual care is not necessarily religious. Religious care should always be spiritual. Spiritual care might be said to be the umbrella term of which religious care is a part. It is the intention of religious care to meet spiritual need.” (Spiritual Care Matters, 2009)

There is a growing shared understanding that ‘meaning making’ and ‘life review’ are important spiritual processes which can manifest themselves in a variety of ways (Mowat & O’Neill, 2013).

Mowat and O'Neill's work is made up of 5 key points:

- There is disagreement and discussion about the definition of spirituality.
- Ageing is a journey which includes a spiritual dimension.
- The spiritual dimension focuses on meaning of life, hope and purpose, explored through relationships with others, with the natural world and with the transcendent.
- The evidence base suggests that genuine and intentional accompaniment of people on their ageing journey; giving time, presence and listening are the core of good spiritual practice.
- Reminiscence, life story, creative activities and meaningful rituals all help the process of coming to terms with ageing and change.

Person-centred care involves spiritual care – the time, attention and listening to support individuals to find meaning and purpose in their lives. It has been established that there are a range of activities and practices which can support these dimensions of spiritual care (Mowat & O'Neill, 2013).

Patricia Higgins argues that for people with dementia, helping to maintain a link or reconnect with their religion as part of their provision of care has the potential to increase their sense of well-being. This has been recognised in the National Service Framework for Older People (DOH 2001) and by NICE/SCIE (2006). Both documents stress the necessity of providing person-centred care that responds to the individual's needs including those relating to spirituality and religion (Higgins, 2011).

## Disability and learning disability

Although the Care Quality Commission carried out a review of Learning disability services in 2011, this did not refer specifically to quality of life or quality of care in residential care settings. Specific literature pertaining to care homes, that do not explicitly refer to quality of life are now being reviewed. Literature relating to disability and learning disability in residential care is again thin on the ground; however, what is out there provides a useful foundation from which to build.

Heather Wilkinson et al's Home for Good? specifically explores those with learning difficulties in residential care who develop dementia. Driving her study is the fact that increasing numbers of people with learning difficulties are living to an older age and, as such, are encountering age-related illnesses and conditions such as dementia.

These demographic changes create pressure on the planners and providers of learning difficulty services. Yet shortfalls in the field are acknowledged and despite these trends, “there is still a lack of useful information and evidence on how best to provide services that are needs-led, multidisciplinary and supportive” (Watchman, 2003).

Wilkinson identifies a number of pathways that might be followed for a person diagnosed with learning difficulties and dementia. These include:

- ‘ageing in place’, where they remain in their own accommodation with appropriate supports adapted and provided
- ‘in place progression’, where staff and the environment are continually developed and adapted to become increasingly specialised to provide long-term care for the person with dementia within the residential service (but not necessarily their own accommodation)
- ‘referral out’, where the person will be moved to a long-term nursing facility or other type of provision (Janicki & Dalton, 1999a; Janicki et al, 2000).

Wilkinson goes on to suggest that according to her survey, even where a formal diagnosis has been given, there is often a lack of any formalised route for the management of the individual’s care, or any consistent or relevant training given to staff (Wilkinson, 2004).

The study’s findings placed emphasis and importance on the following:

- Diagnosis as a starting point
- Pathways of care
- Experiences of co-residents
- The experiences of relatives
- The experience, knowledge and working practices of staff

In a Scotland specific study, but one which has wider implications, the Learning Disability Alliance Scotland (LDAS) looks at concerns that people with learning disabilities might routinely be placed in care homes for older people, overlooking specific needs and tailored care, identifying the potential for a negative impact on both those with learning difficulties and other residents of the home.

The study found a “disturbing picture of crisis management across Scotland.” It suggests that once some people with learning disabilities enter the social care system they face a system of “benign neglect” that they are relatively powerless to do anything about (LDAS, 2010).

“This ‘benign neglect’ where people’s communication needs are unattended, where people’s needs are misdiagnosed, where people are treated as having “challenging behaviour” for listening to “loud” music, where people live for years surrounded by death is a direct result of misplacement in residential Care Homes for Older People” (LDAS, 2010).

LDAS argue that key to addressing change is “proper planning” identifying appropriate care for people with learning disabilities who get older.

A number of recommendations are made in this report to improve planning. “Crisis Management may be acceptable when you have an unexpected crisis but is not acceptable when it is the result of a simple failure to plan” (LDAS, 2010).

The LDAS recommend the following:

- Local Authorities should ensure that every adult with a learning disability living in a residential care home has a person centred plan and that every adult with a learning disability living with an older carer has an Individual Emergency Plan which identifies what could be done in specific crisis situations.
- The Scottish Government needs to look at the care of people with learning disabilities who have dementia and to make a plan for how this should be supported and managed on a national scale.
- The Care Commission should ensure that communication elements of the National Care Standards for people with learning disabilities are applied in EVERY situation where a person with a learning disability is resident in a care home.
- The Scottish Government should ensure every person with a learning disability resident in a care home for older people has the opportunity to access independent advocacy services.
- The Social Work Inspection Agency should review the practice of placing adults with learning disabilities in care home for older people (LDAS, 2010).

## Sensory Loss

According to research by the Welsh Local Government Association (WLGA), there will be an 11.25% increase in the prevalence of sight loss in the next 10 years, correlating to an ageing population and a growing incidence in key underlying causes of sight loss such as obesity and diabetes (WLGA, 2012).

1 in 6 people are estimated to be affected by hearing loss in Wales, a figure that increases dramatically with age – 70% of 70 year olds have a form of sensory loss, for example, rising to 80% for 80 year olds and 90% for 90 year olds (Action on Hearing Loss, 2010). The majority of those with hearing loss are older people and the prevalence increases with age: 71.1% of those over the age of 70 are living with hearing loss (Action on Hearing Loss, 2011). According to the Medical Research Council (MRC) there will be a 14% increase in prevalence every 10 years (Action on Hearing Loss, 2011), again correlating to an ageing population. The World Health Organisation estimates that by 2030 adult onset hearing loss will be in the top 10 disease burdens in the UK, above diabetes.

It is estimated that 18,850 people in Wales are currently affected by both visual and hearing impairments. 62% of the deafblind population is aged over 70 (Welsh Government, 2012).

The links between dementia and sensory loss are well evidenced. According to RNIB, at least 2.5% of people will have both dementia and sight loss by the age of 75<sup>10</sup>. As the population ages, the number of people with both dementia and sight loss will increase<sup>11</sup>.

In care homes, studies indicate a higher proportion of residents may have both conditions. People with mild hearing loss have nearly twice the chance of developing dementia compared to people with normal hearing. The risk increases threefold for those with moderate and fivefold for severe hearing loss. People with advanced dementia will often have sensory loss as a result of age related eye conditions and / or damage to the brain due to the disease (SCIE, 2012).

A recent Social Care Institute for Excellence report, Dementia and end of life care: implications for people with sensory loss (SCIE, 2012), examines the issue; the key points to emerge from the report are:

- People with dementia often suffer from a range of sensory losses –

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<sup>10</sup> Dementia and Sight Loss Interest Group / Vision 2020: The right to Sight UK: Dementia and Sight loss Factsheet. [www.vision2020uk.org.uk](http://www.vision2020uk.org.uk)

<sup>11</sup> *ibid*

especially of sight and hearing – which can be mistakenly ascribed to their dementia. If these losses are identified and addressed by those caring for them, the quality of life of people with both dementia and sensory loss can be significantly improved.

- People with dementia at the end of life will often be unable to communicate their wishes. This makes it especially important to diagnose dementia early and to produce advance care plans – although everyone has the right to refuse to make these plans.
- It is difficult to identify when someone with dementia is approaching the end of their life. However, there are some clinical signs that indicate that someone is entering the final phase of life.
- Care home staff often lack the training and confidence needed to support people with dementia at the end of life. Experiential learning to help them see the world from the resident's perspective can be valuable.
- When a relative is dying, it is a difficult and stressful time for carers. They need support to make the difficult decisions they face.
- It is vital that staff provide individual, person-centred care that is integrated with external services.
- As well as other health care services, care home residents are not always getting access to the specialist palliative care services they need.
- Good design of the environment can play a big part in helping people overcome some of their sensory and cognitive problems.
- A guiding principle in designing living environments should be to favour the domestic and familiar wherever possible.
- Everybody – including staff, residents and carers – should be involved in environmental design. (SCIE, 2012).

The evidence suggests that there is a pressing need for more to be done to meet the needs of those with sensory loss living in residential/nursing care. Sensory loss can have a significant impact on older people's quality of life, particularly within care homes, and can lead to loneliness, isolation and depression (Age UK, 2011a)

Given that such a high proportion of older people in residential/nursing care have some form of sensory loss, there is a strong suggestion that a large

number of older people could be missing out on essential assistance and support (Katz, 2011).

The Social Care Institute for Excellence (SCIE) recognises that reablement leads to improved health and wellbeing of older people living in care homes and also reduces the expenditure required for on-going support<sup>12</sup>. By enabling older people to do things for themselves in care homes, as opposed to doing things for them, their independence is not only increased but their individual outcomes also improve. SCIE has stated that people that have accessed reablement services welcome the emphasis on helping them to gain independence and better functioning<sup>13</sup>.

## Gender Differences

McCann et al explores gender difference in her article, 'Gender differences in care home admission risk'. The background to this study is based on evidence that older women have a higher risk of care home admission than men, this difference remains even after accounting for variations in health. A likely reason for this is the difference in social support provided by spouses. Older men may provide less care for their wives than women do for their husbands (McCann et al, 2012).

The study assesses two explanations for this:

- older men are less willing to undertake traditionally feminine caring roles.
- older men are less physically able to provide care.

This is a Northern Ireland specific study which followed 20,830 couples over a 6 year period during which time there were 415 (participant) care home admissions. As is suggested by McCann, women had a higher admission risk; however, there was no gender difference after adjusting for partner's age.

The results of McCann's study suggest that advanced age and physical frailty explain why men provide less care for their partners than women do; rather than being unwilling to undertake a caring role. The narrowing gap in life expectancy between men and women may have an effect on the future demand for formal care (McCann et al, 2012).

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12 Social Care Institute for Excellence, At a glance 52: Reablement: key issues for commissioners of adult social care <http://www.scie.org.uk/publications/atagance/atagance52.asp>

13 Social Care Institute for Excellence, At a glance 52: Reablement: key issues for commissioners of adult social care <http://www.scie.org.uk/publications/atagance/atagance52.asp>

## Welsh Language

No specific literature pertaining to use of the Welsh language (and particular language needs) and care homes has been found; however, Gwerfyl Roberts (et al) produced a toolkit for the Welsh Assembly Government in 2011. Dignity in Care: Giving Voice to Older People -

Welsh Language Toolkit focuses on the importance and centrality of language in maintaining dignity in care in the bilingual context of Wales, particularly in the care of the older person and those with dementia. The pack responds to a gap in the literature and policy lead on the significance of language awareness in the current dignity agenda. Moreover, it helps align and embed Welsh language services as an important aspect of person-centred care.

Aimed primarily at carers and managers, educators and trainers, it offers key messages that underpin a quality service and tools to guide a best practice approach.

An overview of annual monitoring reports submitted by the principal health organisations in the NHS to the Welsh Language Board during the period 2009-2010 (Welsh Language Board 2010) recommended improvements within organisations around proactive Welsh language provision, training, workforce development and planning.

Since that time, the Welsh Language Commissioner, an independent body established by the Welsh Language (Wales) Measure 2011, has been appointed.

The principle aim of the Welsh Language Commissioner is to promote and facilitate use of the Welsh language. This entails raising awareness of the official status of the Welsh language in Wales and by imposing standards on organisations. This in turn will lead to the establishment of rights for Welsh speakers.

The Welsh Language Commissioner's work is underpinned by two key principles:

- In Wales the Welsh language should be treated no less favourably than the English language
- Persons in Wales should be able to live their lives through the medium of the Welsh language if they choose to do so.

Given the significance of language and cultural awareness in preserving the dignity in care of older people, there is scope for further work to align these key concepts and drive the dignity programme in Wales (Older People's Commissioner for Wales, 2011).

In light of the Welsh Language Act (1993), Public Services across Wales have a legal and statutory responsibility to provide services through the medium of Welsh as well as English, giving equality to both languages. This is reflected in their Welsh Language Schemes that offer clear policy commitments and action steps for implementing and monitoring Welsh language services. The Welsh Government has developed "More than Just Words...." (2012) a Strategic Framework for Welsh language services in health and social services.

The Framework outlines the current position and provides a systematic approach to improve services for those who need or choose to receive their care in Welsh. The supporting Action Plans detail the practical steps needed to strengthen Welsh language services and ensure that they are mainstreamed into all service planning and delivery (Welsh Government, 2012a).

The role of the Welsh Language Commissioner is crucial to ensuring implementation of this framework. The framework clearly states that the duty of ensuring that public organisations meet statutory requirements is now in the hands of the Welsh Language Commissioner.

To this end, the Welsh Language Commissioner has published statutory advice on Contracting Out Public Service Contracts and the Welsh Language. This aims to assist public bodies to commission services that operate a principle of equality for Welsh speaking users.

## Human Rights

"Human dignity is inviolable. Age and dependency cannot be the grounds for restrictions on any inalienable human right and civil liberty acknowledged by international standards and embedded in democratic constitutions." (European Charter of Rights and Responsibilities, 2010)

An important aspect of the Commissioner's Review will be to look at the quality of life and care in residential care from a human rights perspective. Quality of life and care should be underpinned by human rights values. As Professor Judith Phillips argues, "On an international level the Universal Declaration of Human Rights sets out the framework in which care should be viewed" (Phillips, 2007). Although unstated for the most part, the literature

reveals a fundamental understanding of this as reflected in the main themes. For example, My Home Life looks at 8 best practice themes, all of which are rooted in the protection afforded by human rights.

The Declaration of Rights for Older People, published this year, translates high level articles into real scenarios for older people. The Declaration, which has its roots in the European Convention on Human Rights, and Human Rights Act 1998 and the Equality Act 2010, is made up of 6 statements that reflect the rights of older people which they have stated are often ignored. The Declaration aims to ensure that statutory bodies and service providers who work for, or on behalf of older people know what is expected when providing services for older people. The Welsh Government has committed to work with the Older People's Commissioner for Wales and a wide range of stakeholders to develop an Action Plan for the Declaration.

In May 2010 a European Charter of rights and responsibilities of older people in need of long-term care and assistance was launched as part of the EU's Strategy to combat Elder Abuse (EUSTaCEA Project) and this has clear and distinct links to the Welsh Declaration of the Rights of Older People.

The aim of the Charter is to:

- Promote the wellbeing and dignity of older dependent people by **complementing and supporting** the charters and other measures which are already implemented in some countries of the European Union.
- **Raise awareness** among a wider public, to stress the rights of the increasing number of people receiving long-term care.
- **Foster best practices** in Member States and beyond.
- Become a **reference document** setting out the fundamental principles and rights that are needed for the wellbeing of all those who are dependent on others for support and care due to age, illness or disability.

#### Review considerations:

- Human rights principles require a holistic approach to social care so that older people are treated in a manner that is person-centred, recognising their emotional and social well-being as well as medical and personal care needs (Northern Ireland Human Rights Commission, 2012).

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- The UN principles for Older Persons are an important and powerful statement of the human rights protection afforded to older people, and are designed to influence national policy. There is scope for wider use of these principles in Wales in policy-making and practice (British Institute of Human Rights, 2010). The creation of a Declaration of Human Rights for older People is a step towards making human rights more tangible and meaningful to older people in Wales.
- The right to respect for private life should be embedded in the philosophy relating to the staffing and management of a care home and used to ensure that older people are able to maintain fulfilling and active lives and make their own choices as far as possible when in residential care (British Institute of Human Rights, 2009).
- Human rights issues that are particularly relevant should include:
  - Respect for older people's choices in their everyday activities
  - Provision of social and recreational activities and/or support to access such activities
  - Ability to form or maintain personal and sexual relationships
  - Respect for cultural needs, such as religious practices or dietary requirements (these kinds of issues may also fall under freedom of thought, conscience and religion).
  - The right to respect for family life may also apply if restrictions are placed on family life while in residential care or hospital – for example, restricting family visits or not allowing older couples to share rooms.
  - The right to respect for private life can be used to ensure that older people are able to maintain fulfilling and active lives and make their own choices as far as possible when in residential care (British Institute of Human Rights, 2009).

## The Landscape in Wales

In terms of a focus on commissioning, regulation and inspection in Wales, the Welsh Government has announced its intention to introduce new regulation and inspection legislation ‘to give people a stronger voice and more control over their care’. This will be an important lever for change that will relate directly to the findings of the Commissioner’s Review.

A key predicator to Welsh Government’s white paper on the regulation and inspection of care and support in Wales was the National Assembly of Wales Inquiry into Residential Care for Older People (Health and Social Care Committee, 2012) which provides a Wales-specific perspective on quality of life and care in care homes. The report examines the provision of residential care in Wales and the ways in which it can meet the current and future needs of older people. Following extensive evidence gathering, 13 specific recommendations were made to Welsh Government. It also highlights a number of factors that are pivotal in the provision and maintenance of good quality care. These include some common areas of overlap picked up throughout this literature review; such as: Involvement in decision-making; Partnership working; Activities and Interaction; Care home design and Staffing.

While Welsh Government’s response to the Health and Social Committee’s report clearly indicates that it takes the committee’s recommendations seriously and that there is real intent to drive forward the quality of lives for older people; as reflected in the Welsh Government’s wider legislative commitments. Many of the report’s recommendations have not been taken forward and the Older People’s Commissioner for Wales is on public record as stating that Welsh Government’s response fall short of her expectations for the care and support that older people should be entitled to.

The Commissioner has therefore expressed a desire to use the Committee’s report as a key reference point for her Review in particular key Recommendation 7 as critical to improving the quality of life of care home residents.

Notwithstanding this there is much to welcome in legislative developments, the National Outcomes Framework, which sits under the Social Services and Wellbeing (Wales) Act 2014. A new legislative framework that seeks to ensure the provision of high quality social services across Wales and has used a National Outcomes Framework to place a focus on the outcomes of people and carers in need of care and support at its heart. Naturally the impact that the Act will have, will be down to the detail of regulations and the use of meaningful tools to translate wellbeing outcomes into real and tangible

change for older people across Wales.

**Considerations for the Review:**

The potential impact and lived reality of legislation is an issue which the Commissioner can review and scrutinise in line with her powers to review the adequacy of the law in terms of its ability to protect and safeguard the wellbeing of older people. The Commissioner will therefore need to consider how she communicates her expectations for the development of the Regulation and Inspection Bill and regulations underpinning the Social Services and Wellbeing (Wales) Act 2014, both during and beyond the Review.

# Appendix 1: The Senses Framework

## The Six Senses

### A Sense of Security:

- For older people: Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain and discomfort.
- For staff: To feel free from physical threat, rebuke or censure. To have secure conditions of employment. To have the emotional demand of work recognised and to work within a supportive culture.

### A Sense of Continuity:

- For older people: Recognition and value of personal biography. Skilful use of knowledge of the past to help contextualise present and future.
- For staff: Positive experience of work with older people from an early stage of career, exposure to positive role models and good environments of care.

### A Sense of Belonging:

- For older people: Opportunities to form meaningful relationships, to feel part of a community or group as desired.
- For staff: To feel part of a team with a recognised contribution, to belong to a peer group, a community of gerontological practitioners.

### A Sense of Purpose:

- For older people: Opportunities to engage in purposeful activity, the constructive passage of time, to be able to pursue goals and challenging pursuits.
- For staff: To have a sense of therapeutic direction, a clear set of goals to aspire to.

### A Sense of Fulfilment

- For older people: Opportunities to meet meaningful and valued goals, to feel satisfied with one's efforts.
- For staff: To be able to provide good care, to feel satisfied with one's efforts.

## **A Sense of Significance:**

- For older people: To feel recognised and valued as a person of worth, that one's actions and existence is of importance, that you 'matter'.
- For staff: To feel that gerontological practice is valued and important, that your work and efforts 'matter'.

(Based on Nolan 1997)

## Appendix 2: Camberwell Assessment of Need for the Elderly (CANE) tool

The CANE is a comprehensive, person-centred needs assessment tool that has been designed for use with older people. It can be used for both the overview and comprehensive assessments of the NSF single assessment process and is listed on the Department of Health website. It is suitable for use in a wide variety of clinical and research settings and has been used across the UK and in over 25 other countries and translated into 13 languages. It has good validity and reliability and has been extensively field tested.

The CANE has a person centred approach which allows views of the professional, user, and carer to be recorded and compared. The instrument uses the principle that identifying a need means identifying a problem plus an appropriate intervention which will help or alleviate the need. The CANE models clinical practice, and relies on professional expertise for ratings to be completed accurately. CANE administrators need to have an adequate knowledge of clinical interviewing and decision making, and available services. When the relevant clinical and social information has been collected completion of the CANE should take 15 to 30 minutes. Administrators should also have good working knowledge of the concepts of need, met need, and unmet need. This knowledge can be gained with experience of full CANE assessments and reference to the manual. There are 24 topics relating to the user (for example, mobility, self-care, company) and two (A & B) relating to the carer. Ratings for each topic can include one or more of the user (U), staff member (S), carer (C) or rater (clinician/researcher) (R) to allow for the range of views. The standard rating for clinical practice is the staff assessment.

**SECTION 1:** This section aims to assess whether there is currently a need in the specific area. A need is defined as a problem with a potential remedy or worthwhile intervention. Ratings for each area are no need, met need, unmet need or unknown. An unmet need can be for a type of care or intervention or for assessment. If met need or unmet need is identified complete the other sections – if not go on to the next topic area.

**SECTION 2:** Covers assistance from informal sources during the past month such as family, friends or neighbours,

**SECTION 3:** Asks whether the user receives any help from local services to help with the problem.

**SECTION 4:** This asks whether the person feels that the user is receiving the

right type of help with the problem and about the user's satisfaction with the assistance they are receiving.

**SECTION 5:** This section is for notes on the problem and the details of the help/services the user receives and requires, and an action plan. It also allows space for consideration of religious/cultural issues and how the persons own strengths and abilities contribute to the overall picture.

University College London, retrieved from: <http://www.ucl.ac.uk/cane/#uses>

## Appendix 3: Best practice framework for minority ethnic older people in care homes

### Care management plans:

- Improve service user involvement in care decisions and ensure that services are sensitive to the needs of minority ethnic older people, e.g. regular resident meetings to assess both communal and individual needs.

### Service information:

- Increase the provision of information in various languages, styles and formats.

### Communication:

- Facilitate verbal and non-verbal forms of communication and social interaction between older people and care-home staff e.g. understanding the significance of hand and body language and facial expressions.

### Activities and interests:

- Facilitate collaboration and involvement of local ethnic minority communities and organisations in the provision of care.
- Ensure that social, religious and cultural preferences are accommodated in the occupation of leisure time.
- Ensure adequate provision of the physical environment to support social, religious and cultural preferences.

### Alternatives to medication:

- Acknowledge and meet the needs of residents who wish to withhold and/or find alternatives to medication if they prefer or when conflict occurs with religious, social or cultural views.

### Cultural competency training:

- Ensure that cultural competency training is provided, including knowledge of actual and potential service requirements of minority

ethnic older people.

- Facilitate staff knowledge of services which specifically cater for minority ethnic older people.
- Integrate and support minority ethnic care home staff.

**Cultural identity:**

- To improve the understanding and role of ‘community’, dress, food and language in maintaining cultural identity.
- To increase the understanding of minority ethnic older people’s expectations of insight of cultural beliefs
- Acknowledge different styles of end-of-life arrangements.

(Mold et al, 2005b, p604, British Journal of Nursing)

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