Our Shared Vision for My Life at Home in Southwark

Quality of life for those who need care is distinct from quality of care. Quality of life is about recognition and involvement of the individual and the need to connect with them through a healthy relationship in order to provide a truly personalised service. This raises the bar on their experience of care beyond best practice. The following eight themes, clustered under the headings of Personalisation, Transitions and Transformation are derived from the 'My Home Life' [1]evidence base are felt by home care stakeholders in Southwark to be "human themes" which relate to the care of any older person wherever they live. Combined with the Six Senses Framework [2] which identifies a sense of **safety, continuity, belonging, achievement, purpose, and significance** being crucial for anyone to have quality of life, they are seen as the bedrock to support planning.

In order for this to truly achieve quality of life for those who need care in their own home, it is critical to apply the Six Senses Framework to home care staff as well as the users and carers at home. This will lead to health relationships, which is at the heart of 'relationship-centred care'. **The quality of life of all three parties is inextricably linked.**

PERSONALISATION: (*SEE ME*)

1. Maintaining identity

People who have care delivered to them in their own home value the opportunity to have this choice, as long as their identity within the space that is theirs is respected.

Being cared for at home is all about maintaining a person's identity, which for someone with care needs, will be closely associated with what we understand by "home". This may be the place where a person brought up their family, where the story of their life is reflected through photographs and possessions collected over years and through the style and decor of their dwelling. A person's home reflects who they are. It is sacred to the individual and those entering this space are there by invitation.

2. Sharing decision-making

A health, equal relationship between the person who needs care, a relative and/or friend, the home-care worker and any other involved professional (e.g social worker/community matron), means that there is a ***shared*** *responsibility for the decisions to maximise a quality of life for the service user.*

This should happen naturally when professionals are invited to care for people in their own homes. Care workers can be fearful of issues relating to health and safety, or

[1] www.myhomelife.org.uk My Home Life: Quality of Life in Care Homes published by Help the Aged 2006
[2] Mike Nolan et al. Sheffield University. 2006. The Six Senses framework underpinned the DH DignityCampaign.

abuse and safeguarding which can make workers risk averse. People at home want to do “normal” things like us all. We must manage risk together, not avoid it, this requires us to be open-minded and imaginative. However, there must also be clear accountability for the person’s wellbeing by the provider and commissioners. We must get to know the user and their family carer, their families, networks and other professionals and communicate well to ensure that everyone knows what’s most important to the service user so they can live the life they wish. Starting with the service user, this is done by negotiating who bears responsibility if anything should happen to them, and incorporated into their care plan. Care workers need to understand issues relating to mental capacity in order to be clear when it is appropriate for decisions to be made on behalf of someone, in their best interests. This can be a fine balance for people with, for example, dementia or stroke and care workers must be adequately trained and supported by their employer and other professionals.

3. Creating communities

A personalised service requires a means for the user to stay connected within their community, whatever this means for them, to prevent isolation and loneliness and promote the sense of belonging.

This relates directly to a service user’s Support Plan. Linking with the previous themes: the connections we have with our communities are a wider reflection of who we are, the choices we make and the relationships we have. Attending to these will help reduce the risk of depression and self-neglect which typically follow isolation and loneliness. When a person has care needs, they need their community to promote independence and choice, whether it’s for shopping, activities or just being sociable, and this should be covered in the Support Plan. For a home care worker to be “the ears and eyes of the Council”, they must be aware of the user’s links and contacts with the wider community and keep a weather eye out for these links to be maintained. Care at home is not just about visiting and doing tasks, it’s being mindful of the uniqueness of the individual and their belonging in their community.

NAVIGATION: *(CONNECT WITH ME)*

4. Managing transitions

We are all on a journey through life and the changes in circumstances, environment and health have increasingly significant impacts as we get older. The changes affect us emotionally and care professionals need to recognise and understand the impacts of loss and change on service users, where they are in their life journey and the importance of the continuity of relationship and good communication.

Transitions at home can be related to changes in personal circumstances which can lead to the need to engagement with services in different locations. Examples of the changes for older people are: retirement, loss of spouse/friends, increasing frailty, loss of independence, memory, relationships with friends. A person can easily become isolated in their own home. The requirements to make new relationships, with possible needs for care and support after experiencing loss may mean going to a day centre, having respite admissions to a care home or needing to go to hospital. Reablement is another example of a transition requiring an adjustment of approach from carers.

Managing transitions for people who have home care is about recognising loss, recovery, change, bereavement and helping a person bear the pain of grief of the losses. Home carers can help a person make the transition from home to care home/hospital and back again. Continuity of the relationship with home carers is crucial to help manage transitions well. This is about knowing how to work with someone, their idiosyncrasies, their preferences, remembering to make sure they have their personal effects that are meaningful to them when going somewhere new.

5. Improving health and healthcare

More of us are living longer which means an increased incidence of age-related conditions. Care services need to be able to respond to more demand in numbers and complexity of cases. Healthcare services must support home-care workers on the frontline and work with their patients in a relationship-centred way.

Very older people (85+) living in at home have a range of healthcare needs. The changing eligibility criteria and our increasing longevity mean that many people being looked after at home have substantial and complex needs which require the full range of healthcare services.

This is a major issue national issue. The gaps between health and social care affect people's quality of life at home. The user expects their care to be "seamless" and ideally, integrated. Some basic principles need to be shared and agreed. The care workers need to be well supported by the NHS (G.Ps, community matrons and the local acute trust). The expectations of care workers from other professionals and the public are increasing as more of what were traditionally 'nursing tasks' are now sitting with care workers – how is this supported and acknowledged?

6. Supporting good end-of-life

When asked, most people who live at home wish to die at home or in a hospice with their loved ones with them and it's a relief for them to discuss their wishes. In practice, most people die in hospital or a care home.

In society, there is a strong taboo about talking about dying and death, but it is important to have opportunities for discussion around this subject at a time conducive to older people. Home care workers could be the most appropriate people to open up these discussions with an older person which are very important to the individual and can be an unexpressed worry and emotional burden, being a barrier to quality of life. All involved in caring for older people should develop a "good death plan" with the person so that everyone knows what the person wants when they die. Their expectations can be heard and respected and they are more likely to die with dignity. This will benefit relatives and care workers as well as it's much easier to bear the loss of someone when preparations are previously made. It's crucial that care workers and families understand what to do to avoid unnecessary admissions to hospital so people can die at home but also understand when treatment is required. For example, if something happens outside what is expected or if it is not related to the illness / disability. Care workers at home need to know about Advance Care Planning (from the End of Life Strategy) so they can work with users and their families on this. There are practical issues with this. More understanding is needed on the therapeutic aspects of

care and support planning. This theme is closely related to the previous theme as a good death at home needs a joined-up multi-disciplinary team approach involving palliative care expertise.

TRANSFORMATION (*INVOLVE ME)*

7. Our workforce

Our workforce in social care provides a critical role in our community. Society still fails to recognise the importance and worth of excellent care. This mirrors poor societal attitudes to those who need care. To counter this, home care workers need to be properly trained, valued, appreciated, heard and empowered. A shift in attitudes will create transformational change.

In Southwark, we will recruit and retain the right people with the right attitudes and skills to provide high quality care and support to our service users. Raising the profile of a career in the profession will be our objective to ensure we are attracting and retaining high calibre people to work with older people in their own homes. The workforce in homecare is often expected to deliver quality with limited time to interact with users and without attention being paid to travel time. Many feel undervalued given the stigma attached to the work. They need to be properly trained and supported with fair working conditions that allow them to develop and grow in confidence and be proud of what they do. Our users and carers pick up on this and the lack of value given to care workers reflects badly on them. The way home care is commissioned needs to reflect this, with the users' view of what's most important for their quality of life being at the forefront. This means involving users, carers and providers and harvesting their expertise in the commissioning process.

8. Promoting a positive culture

The care organisations' culture needs to foster the conditions for good leadership and relationship-centred care in order to bring out the best qualities in the home care staff required by people with care and support needs and transform the experiences of service users.

This reinforces the need for the providers to be commissioned in the right way, as the current working conditions for home care workers do not foster the right conditions to create quality of life for people in their own homes. This theme builds on the need to develop and grow the home care staff to meet the increasing challenges of the nature of the work. This must also be addressed by the NHS as well, developing home care staff without involving Health and Social Services will not be enough. Everyone needs to recognise the value of the care workers as equals. Regional managers need to see themselves as potential leaders, not feel victimised.