

Issue 13

Giving people with dementia a voice





My Home Life is a UK-wide initiative aimed at promoting quality of life for those living, dying, visiting and working in care homes for older people, through relationship-centred care and evidence-based practice.

There are eight evidence-based themes for *My* Home Life

- 1. Maintaining identity
- 2. Sharing decision-making
- 3. Creating community
- 4. Managing transitions
- 5. Improving health and healthcare
- 6. Supporting good end-of-life
- 7. Promoting a positive culture
- 8. Keeping workforce fit for purpose

The first three themes are focused on how you approach and **personalise** care. The next three themes are concerned with how you help **navigate** residents and relatives through the journey of care. The last two themes are aimed at managers

to help them support their staff, put the other six themes into practice and thus **transform** care.

This guide is being distributed to 18,000 care homes on behalf of My Home Life through Care Management Matters.

This edition of **My Home Life** was written by Sarah Reed

England: mhl@city.ac.uk 0207 040 5776

Northern Ireland: s.penney@ulster.ac.uk

028 7167 5893

Scotland: myhomelifescotland@uws.ac.uk

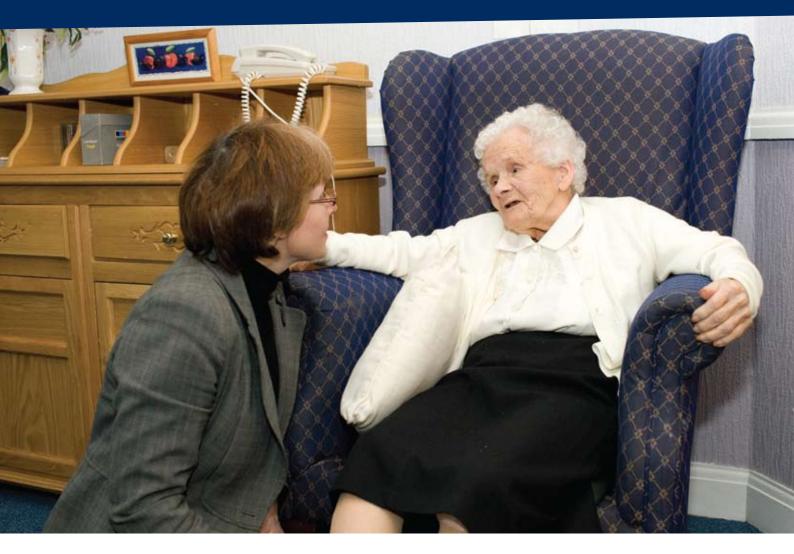
Wales: suzy webster@agecyr

Working together

This bulletin was created in partnership with Dementia UK, a national charity, committed to improving quality of life for all people affected by dementia.



We all deserve to be heard



The importance of good communication and social contact should never be underestimated. But for people living with a dementia, especially in the later stages, this can be a challenge. Care homes play an increasingly important role in supporting older people living with dementia. Through developing strong relationships with residents and relatives, care staff can help older people regain their sense of voice, choice and control over their lives.

Keeping it real

People living with dementia need frequent opportunities to communicate in a meaningful way. It is up to us to make the time to listen, try to understand, and to encourage their efforts even when it is difficult. The potential for quality of life and

wellbeing is in our hands.

Caring for people living with dementia is complex, often testing work. In some respects, their behaviour can be as a mirror, reflecting the interest we show in them and the care they receive.

And of course, every person with dementia is different, and each has their own communication requirements. People with hearing or sight loss, or other health issues, for example, will have their own set of needs; while those from ethnic groups where English is a second language, will have others.

We need to be on 'high alert' to each person's needs, and respond with positive, empathetic communication strategies. This bulletin aims to offer some ideas on how we can best support those residents whose voice can sometimes go unheard.



Two-way communication is central to all good relationships including caring ones, as Shaaron Caratella from Queens Court Care Home explains...

"As dementia reduces people's ability to communicate, it is vital they have daily opportunities to connect meaningfully with others. Making the time to listen, understand and encourage them is vital to restoring a person's sense of self-worth and quality of life.

For carers in a busy care environment, kindly, engaging communication can be challenging to achieve on a minute-by-minute basis. But it can help us interpret residents' behaviour and lead to better relationships, which in turn improves job satisfaction. Like care, it is a two-way street.

For a few years now, we have been encouraging staff to research and create residents' life story albums – which means stopping long enough to listen to them!

We spent time helping staff improve their communication skills, then asked them each to sit with a resident and explore their life story.

We found that the way people talk about their past experiences gives us some understanding of their current attitudes and behaviours, especially their views about care.

The results have been good for everyone here, including residents, staff and relatives. It has helped build mutual affection and respect, and boosted everyone's sense of wellbeing by celebrating residents' past lives."

How well do you communicate?

- 1. Consider the following statements. Then, using marks out of ten (ten being high and one being low) think how you feel about them.
- 2. Now, think how you might answer if you were a resident with dementia.
- 3. Repeat the exercise as if you were a relative or regular visitor to the home.

Compare the results and think about what they tell you. Can you see what is good about the communication and relationships between the three groups, and where improvements could be made? Discuss this with colleagues.

Statement	You	Resident	Relative/ Visitor
People here communicate with me well			
I am often asked questions about my life			
Everyone here is interested in where I come from and what my life has been like			
I feel that my point of view is heard and acknowledged			
I would change almost nothing about the way that people talk to me here			
The best thing about the home is that people are happy here			
Total			

Listen and learn

Listening is key to good relationships, but studies suggest we normally remember a mere 25-50% of what we hear.

The types of conversation we have affect our sense of wellbeing. The happiest people have twice as many deep, meaningful conversations as others, and indulge in significantly less 'small talk'. Real communication means listening, thinking and connecting. As one resident put it, "Being listened to properly, makes you feel that what you have to say is worth something".

At registered care centre Broadmeadow, in Folkestone Kent, Manager Caroline Barber believes that active listening can be surprisingly rewarding.

"Active listening is all about listening



'deliberately', with a positive, interested attitude and without passing judgement," she says.

"In all my experience, asking relevant, meaningful questions and then listening carefully to the answers is key to maintaining successful relationships – not just residents, staff and colleagues, but with friends, spouses and children too."

Find out more about dementia with the *My* Home Life DVDs available at: http://myhomelifemovement.org/dementia/

Bringing up the past

Personal recollections of memories from the past are important to all of us. For older people, especially those with a dementia, reminiscing can boost their sense of identity and general wellbeing.

Talking about the past gives people an opportunity to share historical, cultural or personal information. It allows them to pass on wisdom and skills, and gives them a sense of self-value and importance. It also creates feelings of intimacy and sharing.

The 'Reminiscence Bump'

When older people talk about the 'good old days' they often mean their childhood, teens and twenties. In 1986, US researcher Dr. David Rubin established the so-called 'reminiscence bump.' He demonstrated that people have more memories between the ages of 10 and 30, than at any other time in their lives. That's why people in their eighties/nineties enjoy talking about the 1940s and those in their late sixties /seventies enjoy memories of the 1950s.

Getting the conversation started

- Sight: Family photographs, pictures, objects and images with personal meaning that trigger memories
- 2. Sound: The radio, recordings from a 'reminiscence bump' period, making music using simple instruments, singing well-loved traditional songs
- 3. Touch: Textures, fabrics, ribbons, buttons, sculpture, pottery
- 4. Smell: The smell of coffee, freshly-baked bread, a recently picked tomato, even the



- smell of the inside of a well-used teapot or household cleaning products
- 5. Taste: Different food and drinks; eg a pot of tea made with tea leaves, a homemade jam sponge cake
- 6. 'Mind Albums': Ask for descriptions of familiar places like home, school, a favourite view, a family pet

General reminiscence can take place in small groups, but for people with dementia, one-to-one conversations are often best.

Remember, a person has the right to refuse to join in with any activity – even conversation – but positive encouragement in pleasurable recollections of the past usually leads to a life-affirming, enjoyable experience.

Not everyone has had a happy childhood and not all memories are good. Although they generally recover quite quickly, occasionally, people get upset while reminiscing, particularly about loved ones who are dead. The best response is to just 'be' with them sympathetically, maybe hold their hand, touch their arm gently, or offer a tissue, and reassure them that these feelings are quite normal. The key is not to rush them, but let them move on in their own time.



Can you guess who I am?

A funeral might seem an unlikely place for inspiration, but after hearing all the stories about a deceased resident shared by mourners, one Essex Care Home Manager (Anna Searle) invented a life history game.

"I asked carers to interview a resident and then write a page about their life. I asked them to write it as if they were the resident themselves, keeping all names anonymous. If the resident had dementia and was unable to do this at the time, staff were encouraged to speak with the relatives" she says.

"We then tested ourselves by reading out these stories to see if we could guess who the residents were from their life histories and experiences."

The game turned learning about residents into a fun and enjoyable experience. By encouraging carers to sit and talk to residents, carers had a break from physical tasks and got to know residents better.

The carers said that talking to residents and their families about personal histories helped them to see the person they were caring for. It helped them to understand why person-centred care was so important and also helped to reduce cross-cultural barriers.

Why not think about encouraging staff to do life histories on each other? It might be a way of helping team members to get to know and understand one another better.



For supporting residents with dementia

- 1. Think about body language: Always sit at 90 degrees to the person, so you can look out at the world together and helpfully keep at their eye level. Always re-introduce yourself every time you are with someone with advanced dementia.
- 2. Do it 'with' not 'for' people: Becoming dependent on others can be very upsetting and often leads to deteriorating physical health and wellbeing. Doing things with residents and encouraging them to do things by themselves instead of to or for them, can make them feel less dependent.
- 3. Enjoy activities together: Observing the things we like and sharing them is an activity in itself, for example, "This is delicious isn't it?" or, when you see someone tapping their foot in time to some music, "Does this music make you want to dance?"
- **4. Be calm and self-reflective:** Being self-aware and mindful is key to good communication. Cheerfulness should be balanced with gentle calm.
- **5. Empathise:** Recognising and showing heart-felt concern for someone helps them feel safer and better understood. It also encourages them to express themselves more openly. Always ask yourself how the person might be feeling.
- 6. Remember that people forget: If someone is distressed because they don't remember a loved one has passed away, there is little point in reminding them or getting impatient. Instead, try giving them opportunities to talk

- about what it means to them, for example: "I can see you are upset, he/she was important to you weren't they? What were they like?"
- 7. **Be positive:** Encouraging the other person to continue talking really helps communication. Use positive reactions like, "Yes, I see," or "Uh-huh," "That sounds interesting."
- 8. Shut your eyes and listen: Care homes can be noisy places and this can cause confusion. Keep local noise like the TV, radio or other environmental noise to a minimum. Sight and hearing impairments can reduce understanding, and 'internal noise', like tiredness, anger, sadness or physical discomfort may also cause confusion.
- 9. Just 'be': People tend to withdraw from social interaction in late-stage dementia. They may lose their sense of themselves and sleep a lot. Sitting with someone and looking at their life album together, or just 'being' there together, can help improve their wellbeing.
- 10. Create a life story book: Autobiographical picture albums assembled from the earliest point in their history up to the present day are one of the most useful tools for better communication. Make them easy to read enlarge photographs and add conversational captions in resident's own words, for example, 'This is me with mum' or 'Here's me at school with my sister Connie.'



