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The care home I'd like

The ELSA and LeNeMi projects

Regards croisés sur des pratiques professionnelles infirmières en Europe

Journées internationales

Institut de Formation Interhospitalier Théodore Simon

3, Avenue Jean Jaurès

Neuilly-sur-Marne

Rita Bencivenga, Alessandra Tinti, Licia Nigro

Studio Taf, Genoa

Text translated by Emma Berridge

www.studiotaf.it

“During my time at nursing homes and specialist Alzheimer’s centres, watching what was going on around me, “talking” in a new language using words and fragments of words with a different meaning, observing thousands of tiny gestures and movements, the sense of timelessness and slowness... after a while my own sense of self and my own identity started to become hazy.”

A participant in the Elsa project

A few months ago the European project known as ELSA, Empowering Lives, Supporting Affectivity,¹ came to a close. During the project a series of videos, texts and slideshows was created for professional and non-professional carers assisting the frail elderly, particularly those living with a form of dementia.

The project’s final meeting was held in Genoa, Italy, on Saturday 26 November at a prestigious location, the Palazzo Ducale (Ducal Palace). The Palace is a popular meeting place and is home to exhibitions, conventions, bars, restaurants, shops and information kiosks.

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Instead of a conventional conference, the project partners decided to hold an open day so that they could "present" the project to local people. Project videos were shown and DVDs and brochures were given out to passers-by.

Between 10am and 5pm, people passing through one of the city's main thoroughfares were able to discuss various issues with the partners. Interpreters were on-hand to facilitate the exchange of information with the Scottish, Austrian and Lithuanian partners.

The project: The care home I'd like

To mark the open day, we decided to launch a collection of thoughts and opinions which we called "The care home I'd like".

This is the description of the project which we published online. Leaflets and postcards were distributed throughout Genoa during the lead-up to the open day:

"The care home I'd like. For my loved ones, for myself, for whoever has to spend part of their life in a care home, residential home or any other type of protected community. Help us by compiling your "wish list", which we will publish on the project website: <http://www.elsacare.eu>

[. We will be sharing the wish lists with people who have influence over how care homes for the frail elderly are organised and managed. Send your wish list to \[elsa@studiotaf.it\]\(mailto:elsa@studiotaf.it\)](#)

; please pass this postcard on to anyone else you think might be interested."

"Care home" or "rest home" is a rather generic term. The project was aimed primarily at people coping with much greater levels of frailty and impairments than those who might enter a rest home. To reach our target audience more effectively we could have used the term "nursing home", but we thought that focusing on greater physical and cognitive impairments would greatly reduce public participation. We set out to "bring people in" so that we could talk about the project. We can now say that it was relatively easy to change the subject from a general issue (care homes) to a more complex one (the care needs of people who can no longer live independently).

Even so, we realised that our displays and postcards put off many passers-by. People did not want to talk about ageing issues, particularly problematic ones, regardless of their age.

The frail elderly: a key issue for the city of Genoa

[Data published by ISTAT, Italy's Central Statistics Institute \(ISTAT, 2010\), ^{\[2\]}](#) shows that Italy has the second oldest population in Europe after Germany. Italy has 43% more elderly people than young people.

According to figures from the Commune of Genoa, in 2009 there were 164,264 over-65s living in the city, equivalent to 27% of the population (compared with a national average of 20%). This number has grown further over the past two years. Statistics also show that 31% of elderly people live by

themselves; there are many employment opportunities in the city for caregivers, be they part-time or live-in positions.

ISTAT's demographic forecasts show that the structure of the Italian population as a whole will not reach the numbers of elderly people living in Genoa until 2030.

The city has anticipated population forecasts for the coming decades. It is a natural laboratory where new solutions to the challenges of ageing might be trialled.

Caring for the frail elderly at home or in residential care is one of the greatest challenges facing the city and its social services today.

Feedback from the people of Genoa

Outlined below are some of the seventy-plus comments we collected, with comments that we as "experts" might make. They are followed by some of the comments and hopes expressed by people^[3] coping with dementia and serious physical impairments. Finally, we will concentrate on the concept of "embodied selfhood".

Of the 76 messages we collected, 7 were unsigned, 44 were signed by women (two of which were signed by a man and a woman and one by two women) and 28 by men (including the two signed by a man and a woman).

We sorted them by the main "theme" of each message, although others might arrange them by different criteria:

- Feelings*
- Relationships with staff*
- Activities*
- Facilities*
- Facilities/Staff (messages covering more than one theme)*
- Facilities/Relationships (messages covering more than one theme)*
- Personhood*
- Costs*
- Support services*

Examples of some of the messages:

- Feelings: "I'd like everyone to find their smile again"; "a care home which offers people kindness and smiles"

- *Relationships with staff: "proper training for care home staff"; "skilled, affectionate carers"*
- *Activities: "a welcoming place where animals can visit, where you can listen to music and read together"; "books, 60s music and doing everything I do now"*
- *Facilities: "apartments with shared facilities"; "I'd like elderly people to be able to live at home. When this is no longer possible, I'd like them to be able to live in small houses where things are family-based and human. I'd like this for myself and everyone else"; "a home where I can have company and my own privacy"*
- *Facilities/Staff: "a care home without too many steps, with its own garden, surrounded by greenery. And as little medical intervention as possible"*
- *Facilities/Relationships: "a family home where life is as similar as possible to life in one's own home, where people share things, help one another and become friends"*
- *Personhood: three people mentioned what we might call "personhood": "a place where people's lives aren't organised to suit the care home, but where they can keep their individuality, whatever form it takes"; "a place where there's time to look after our 'old people's' memories as well as caring for them"; "a care home where people are comforted and listened to, and where the guests' wellbeing comes before anything else"*
- *Costs: only one person mentioned the costs: "a reasonably-priced care home! A place which doesn't make profit from the elderly, but respects their dignity"*
- *Support services: only one person mentioned support services: "an information office which answers people's needs so they don't have to seek out help in different places"*.

The view of old age and the ideal care homes which emerge from the comments have little in common with what is available today in Genoa. Most of the people who left comments tended to ignore the idea of frailty, illness and mental and physical impairments which generally lead to elderly people leaving their homes. As far as their comments on facilities and activities are concerned, the general view is closer to the classic rest home which was common until a few years ago. People would go to live there while their physical and mental health was still relatively good, to enjoy a well-deserved "rest" once they were beyond retirement age.

Today people move into care homes when they are much older. The average age of residents is around 80 and their physical and mental health is in much greater decline than before. More specifically, people who are still able to live independently, who can spend their time playing cards, going to conferences and using public spaces as they wish usually still live in their own homes, perhaps with the help of a care assistant or personal caregiver.

We think it would be interesting to carry out a wider study to see whether people really understand what life is like for the residents of nursing and care homes. This might help find communication strategies for the local community, providing greater support for future projects run in and around Genoa by public and private organisations.

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It might also help tackle the problems the city faces due to the lack of places in care homes, as well as improving training and lifelong learning for carers. Carers often have to deal with situations in which dementia and other serious disabilities require more than one-to-one care.

Comments from professional and personal caregivers

Let's look at some of the comments made by those caring directly for elderly people with serious physical and mental impairments.

"We promised we'd never put her in a care home."

"I can't go on anymore. I need to sleep for a few nights otherwise I'll go crazy."

"It's strange. Even though we don't understand each other anymore, we laugh a lot. She was never a happy woman, but now everything's different."

"Even though I'm tired and worried, being with him gives me a sense of peace."

"The new lady reminds me of my grandmother. I'd like to go and hug her but the Director says we must keep our distance from guests."^[4]

Caring for (and worrying about) someone living with a form of dementia, including Alzheimer's, means coping with a series of situations connected to all areas of life: not just emotions, relationships or health.

Unfortunately the typical lifestyle found in many nursing and care homes is still based on the approach used in hospitals or rehabilitation centres.

Residents of care homes – and let's not forget that these are people's homes, not places where they spend a few days or weeks – often have no control over basic rights and pleasures: when they get up in the morning, what they eat, how they spend their day and when they go to bed.

When older people lose the ability to take care of themselves, caregivers often focus solely on physical comfort, safety, hygiene and their immediate environment. These are important issues, but certainly not the only ones.

Above all, this model is far from the person-centred approach which sees each person as an individual.

If the people around a table in a nursing home often seem the same, it is not because of the passage of time or, in many cases, the effects of disease. Even in care environments with the best possible intentions, there is a slow but relentless "flattening" effect which homogenises people:

- *they get up at the same time every day;*
- *they eat the same things, at the same time and all in the same place;*
- *they go to the bathroom at specific times;*
- *they wear their hair short because it's easier to wash it and keep it tidy;*

- *they wear trousers rather than skirts to make it easier for caregivers to change them, and in some cases fleece garments since woollen clothes and similar are difficult to wash and care for in a home;*
- *they always watch the same TV programmes, listen to the same background music, share the same silence...*

None of these situations involves outright aggression or hostility, but we need to ask if people's individuality is really being respected. What does individuality actually mean?

We are all different. Our tastes, preferences, habits and fears vary widely. Yet how can we imagine what they are when someone can no longer explain them, when someone is no longer physically able to push an object away or refuse contact to show that they'd "prefer not". When nine times out of ten what someone says is meaningless to the listener, or refers to things which are only in the person's mind, how can we really be sure that we understand them the tenth time, when their message is comprehensible?

What do we mean when we say that everyone is different? Here are series of fairly common situations which show that there is a host of different alternatives for every one of us:

- *I don't like my food too hot. I always wait until it's cooled down before I eat it.*
- *I'm not scared of injections, but I always worry about having to take a pill.*
- *I don't like people touching my hair.*
- *I've always washed my hair in cold water. I find it refreshing.*
- *When I want to relax, I prefer things quiet. Music can make me cry or make me feel anxious.*
- *If I don't clean my teeth before breakfast, I can't even bear to have a coffee.*

Some people can't get out of bed unless they have a strong coffee, some of us like our food piping hot, some are scared of injections, some would never use a suppository, some switch on the radio as soon as they get home to avoid the silence...

How can someone explain all this if they can't speak, if they can't move around as they'd like to, if no one listens to them? Alzheimer's is often used as a blanket excuse for people's behaviour, moods and reactions.

Expectations are lowered. Compromises can be made on certain things: having coffee instead of tea in the morning; washing your face with a flannel even though you've never liked it; eating two courses at every meal; wearing trousers instead of a skirt... what difference does it make, anyway?

Little by little, the days blend into one and people's lives become standardised.

People can still feel afraid, hurt or disgusted. Recoiling or pushing someone's hand away... small gestures like this seem to reinforce the attention of the person who's washing us, dressing us or cutting our hair. You must co-operate... no one's going to hurt you... you must have your shower, you can't stay dirty!

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More overt gestures, expressions of fear and attempts to get away reinforce the idea that the illness is bringing back unhappy memories from the past... either you are left alone for the moment or efforts are stepped up even more, for everyone's sake.

It would be a good idea to make a list of preferences, fears and anxieties ready for when someone goes to live in a care home or has to have a caregiver at home. But when should it be done? People change as they age, and things we didn't mind at fifty we can't stand at seventy. By contrast, someone might suddenly start to like fish, for example, as they grow older.

Is there any point making a list? Can we expect carers, who work in shifts, change jobs frequently and have dozens of residents to look after, to know every little thing about us?

Who would make the list? The person concerned, family members, friends, or carers who already know something about them?

Is it really impossible to understand someone who can't speak clearly and who doesn't think the way we do?

The person-centred approach

The ELSA project was inspired by the person-centred approach. Based on the observations of Tom Kitwood, it emphasises the importance of treating people as individuals whose life stories, experiences, likes and dislikes help define them as individuals.

People who have difficulty following verbal communications, such as those living with dementia, process messages in non-verbal ways. They can only use non-verbal means to express their hopes, preferences, fears and intentions.

Life in a care home inevitably imposes a certain rhythm, and while this may involve a comfortable standard it is still far from a personalised approach which treats each person as an individual.

Person-centred care focuses on the independence, welfare and empowerment of individuals and families and allows people to feel supported, valued and socially competent.

But to switch to this model, we must all be convinced that people remain individuals even when their mental capacities decline.

We must recognise the centrality of relationships, the uniqueness of the person and that our "personhood" still exists even when we can no longer communicate verbally.

The concept of "embodied personhood"

As part of another project^[5] which launched in August 2011, we are looking into the training needs of people (migrants) wishing to work with the frail elderly. We aim to show how learning pathways can be integrated with training modules so that carers become aware of "embodied personhood".

Training carers to understand the feelings of people who are unable to express themselves through the usual channels helps provide a solution to many situations which are otherwise difficult to handle. The basic concept is that "personhood" persists even when dementia is advanced; when a

person can no longer communicate verbally, he or she retains a form of non-verbal “expression” which, when observed carefully, points to embodied personhood. “People who are cognitively impaired are able to use their bodies for self-expression, providing clues as to who they are and what their needs are,” explains Pia Kontos.[6]

As Kontos’s research has shown, some caregivers instinctively recognise and respond to expressions of embodiment,[7] that is, the fact that even people with advanced dementia express their personhood, desires, likes and dislikes through their bodies. When caregivers are able to recognise this, there are fewer episodes of resistance and an improvement in interactions between the elderly and their caregivers.

Programmes which train caregivers to recognise and respond positively to embodiment have positive outcomes. They reduce the need for “restraints” to manage the behaviour at the root of the problem.

All this helps make care-giving a more human experience. It deals directly with one of the greatest causes of dehumanisation, that is, the assumption that our personality is erased as cognitive damage increases.

“There is no affront to human dignity if you believe that there is no personhood... When people lose the ability to express themselves verbally, their self-expression often becomes equated with erratic, demented behaviour,” explains Kontos.[8]

We must learn to move away from seeing behaviour as a problem to be kept under control and instead to understand the meanings which underlie self-expression in dementia.

It is important to embrace a new approach which respects people living with any form of dementia. We must learn to see them as “embodied selves” who deserve dignity and recognition of their worth, and recognise that they are still able to express themselves.

We are at the beginning of a pathway, but we believe that improvements to the everyday care of the people who trust us and changes to our environments and interpersonal relationships will help lower instances of burnout among professional caregivers and relatives alike.

This pathway can and indeed must be undertaken by family members, caregivers, nurses, geriatric experts, care home managers and even kitchen, laundry and cleaning staff.

^[1] More information can be found on the project website, which also has a section in English: www.elsacare.eu

^[2] <http://noi-italia.istat.it/> “Rapporto Noi Italia, 100 statistiche per capire il Paese in cui viviamo” Published by ISTAT

^[3] These people took part in the project as external consultants, providing Studio Taf with advice on how to design its series of products. The consultants were professional healthcare workers and relatives of elderly people living with dementia, some of whom have had experiences of both conditions. Special thanks go out to all of them.

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[4] These comments can be found in “The ELSA Project: Using Web 2.0 and non-pharmacological approaches to Alzheimer’s”, published in ELSA’s 4th Newsletter at www.elsacare.eu

LeNeMi Learning Needs of Migrants working as caregivers. <http://lenemi.wordpress.com/>

[6] <http://www.torontorehab.com/Research/Researchers/Research-Profiles/Pia-Kontos.aspx>

[7] “The term “embodiment” refers to the series of learned habits and culturally-determined somatic techniques which enable a person to exist within his/her body and the outside world. Unlike “body”, the term “embodiment” refers both to the somatisation of culture and the use of the body in producing cultural and historic forms. In terms of embodiment, the body is not a biological identity alone: it is also an historic and cultural phenomenon. Similarly, culture and history are not simply the product of ideas, representations and material conditions; they are also bodily phenomena.” Text sourced from: Claudia Mattalucci – Yilmaz, Introduction, in “Corpi”. Annuario di Antropologia, edited by Ugo Fabietti, n. 3, 2003. For further information on the concept of “embodiment”, see the following authors and texts: Thomas Csordas: “Embodiment and Experience”; Pierre Bourdieu: “The Logic of Practice” and “Outline of a Theory of Practice”; Merleau-Ponty: “Phenomenology of Perception”.

[8] <http://www.cihr-irsc.gc.ca/e/43510.html> last visited May 15, 2011



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