

# Dignity in Dementia

## Dementia emergency app for 999 responders, neighbours and family carers

**Dignity in Dementia identified the need for a quick guide for emergency services, community members and relatives – who are often the first responders when a person with dementia is disoriented, confused and anxious.**

**This social enterprise worked in partnership with police, fire and ambulance services, and dementia experts to develop an app, and supporting website, featuring common crisis situations and a step by step approach to resolving them calmly and swiftly.**

**The [Dementia Emergency website](#) includes advice and guidance available to download as electronic documents. The app works without internet access and is freely available to download from [iTunes](#) and [Google Play](#).**

Dignity in Dementia is based in South Cumbria and employs two full-time staff and a small number of associates.

Since March 2014, their aim has been to enhance the dignity of people living with dementia, and that of their caregivers. They provide training to health and social care organisations, run dementia-friendly singing groups in two rural towns, and deliver project-specific work that improves the quality of life for

people who need care and support. Dignity in Dementia promote practical approaches that can easily be used to improve the well-being of both people with dementia and those who care for them.

Their work includes care programmes for family members, carrying out emotional trigger assessments to identify and reduce the causes of challenging behaviours.

These can arise when a person's psychological or emotional needs are not met. One example of this is a man who was repeatedly leaving his residential care home at 4am and walking the streets. There was concern from care staff and other residents as he was an elderly person who could become disoriented. The police were called out repeatedly to find him and bring him safely back. The man was a retired postman, and in his mind, he was going to work. Once the care staff gave him a 'sorting room' and their post to sort, the walk-outs stopped.

Dignity in Dementia approached Cumbria Constabulary to help reduce the number of repeat call-outs for dementia-related incidents, and delivered dementia training for front-line police personnel. While the training was well-received, they realised a key challenge was the potential time-delay between officers attending the course, and putting the learning into practice.

## What we wanted to achieve

Dignity in Dementia realised the emergency response training would naturally fade if there was a long gap between the course and the next call-out. They wanted first responders to have practical guidance at their fingertips.

Although all people living with dementia will experience it differently, common emergency situations do arise, for example where the person is missing from home, believes an intruder is in their house, or believes something has been stolen from them.

There are also common factors affecting the physical health of a person with dementia:

- reduced field of vision or accentuated hearing
- lack of understanding can lead to first responders making a situation worse by increasing the distress of the person experiencing the crisis.

Dignity in Dementia wanted to create a guide with simple steps to effectively approach a person with dementia, reduce their anxiety, and gain their trust.

The aim was to produce an app was designed to improve person-centred care and support for people with dementia. Their target users were police, fire, and ambulance personnel, family carers, neighbours and community-based care staff.

Their aim was to give 999 responders, neighbours, and relatives the knowledge and confidence to effectively assist in a dementia-related emergency.

The information on the app and website is easy to read and follow. Knowing how to approach a person in a way that won't scare them or make them more anxious is hugely beneficial.

Sgt Bill Nolan, Cumbria Constabulary

## What we did

Dignity in Dementia partnered with a local college, who were able to undertake the technical aspects of the project.

They began by gathering information from their target users – consulting with range of emergency service personnel to understand the types of dementia crisis situations their staff had attended. They also consulted with health services, and family carers. This knowledge base formed the content for the app and website.



Dignity in Dementia used their professional experience together with learning from dementia experts to provide guidance in relation to each of the scenarios.

## What we achieved

The app and website were well received beyond the initial target users in the emergency services, and the number of downloads continue to increase. By July 2016 the app had been downloaded 1400 times, and the website had more than 5000 views.

Dignity in Dementia reported South Cumbria domiciliary care agencies had requested their staff download the app to their work phones. Website and app usage reports show the app has been downloaded nationally and also worldwide in countries such as Brazil, Spain, USA and Australia. Users have reported feeling more prepared and confident to approach dementia-related emergencies.

## What we learnt

- identifying named individuals in the emergency services who saw value in the project was particularly useful. Initially this had been a barrier as contacts moved on due to restructures etc.
- There were many scenarios that could have been included in the project, with complicated guidance. Therefore both the scenarios and guidance needed careful editing

The dementia emergency app is excellent! Thank you. I have forwarded it to all my mum's carers.

Sgt Bill Nolan, Cumbria Constabulary

Many patients and carers are less likely to venture out as they worry about an emergency situation occurring such as forgetting where home is.

They and their family with the help of the app, will be able to plan as best they can for 'unplannable' emergency situations and will hopefully feel more empowered.

Stella Carradice, Care Navigator,  
Kendal Integrated Care community.

- a key challenge was in keeping the language simple and easy to understand, rather than using specific medical terms
- forming a strong relationship with the technical team was crucial to successful delivery of the resources. Through close communication Dignity in Dementia gained insight and guidance to the technical aspects of website and app development. This meant there was an effective process in place for requesting and implementing changes throughout the development cycle
- project stakeholders make the best advocates and advertisements for the final products. We encouraged all of our stakeholders and consultation groups to feel ownership of the resources, and to use their communication channels to promote the app and website.

## For more information please visit:

<http://www.dignityindementia.org/>

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## Skills for Care recommends

From activity provision and dementia qualifications to associated guidance, Skills for Care produces various resources to strengthen care worker skills and enable better care provision.

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### Common Core Principles for supporting people with Dementia

We have produced a guide which supports the social care and health workforce to care for people with dementia. Employers should use the principles as part of their development plans to improve the experience of those with dementia and their carers.

[www.skillsforcare.org.uk/Documents/Topics/Dementia/Common-core-principles-for-dementia.pdf](http://www.skillsforcare.org.uk/Documents/Topics/Dementia/Common-core-principles-for-dementia.pdf)

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### Dementia and other conditions

This series of case studies highlight how to care for people with dementia and other conditions, including Parkinson's disease, sensory impairment, learning disabilities and long term pain management.

[www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-other-conditions.pdf](http://www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-other-conditions.pdf)

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### Further Dementia Resources

These include how to identify dementia, how homecare workers can support people, with dementia, diversity and dementia and free e-learning.

[www.skillsforcare.org.uk/Topics/Dementia/Dementia.aspx](http://www.skillsforcare.org.uk/Topics/Dementia/Dementia.aspx)

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