

### **The Partnership Project**

For several years I have been running creative writing workshops with a wide variety of community groups. When the opportunity arose to be involved in a multi-disciplinary writing project, I was interested to discover if I could use the same skills and approaches with older people with dementia.

In 2011/2012, a unique collaboration between New Writing North and Newcastle University Changing Age Team resulted in a project combining writers, scientists and older people with dementia. The aims were to raise awareness of the issues facing those with dementia and to highlight Newcastle University's leading role researching the ageing process.

The project was innovative in combining the skills of three writers: Romi Jones, prose writer, with scriptwriter Fiona Evans and Rebecca Jenkins, novelist and cultural historian. Each writer spent twenty sessions with older people with dementia in an Alzheimer's Society day centre and Age UK Newcastle lunch club. Each writer also spent several sessions with scientists/clinicians working with older people with dementia and researching the ageing process. Additionally, all three writers had first-hand experience of dementia in their own family.

The symptoms of dementia include memory loss and other functional difficulties which reduce independence, sometimes bringing challenging behaviour. It is common for relatives to say '*I feel as if she has already gone.*' or '*He's no longer the man I knew.*' In this project, all three writers were keen to capture the '*self*' evident in each individual person through the minute-by-minute joys, perceptions, opinions and challenges that demonstrated their individual spirit, regardless of their cognitive functions.

The outcomes from the project were three different but complementary literary forms. Fiona Evans' play *Geordie Sinatra* was performed at theatres in

Newcastle-upon-Tyne and Scarborough. Rebecca Jenkins created the animation *What About Me* on YouTube. For myself, I had already considered that flash fiction would be an appropriate form because its short, punchy style reflects the fragmented memory and speech patterns of people with dementia. My series of six flash fiction stories, *Dementia Dilemmas*, captured the issues raised during the time I spent with the people in the day centre. Each short, short story was printed on an A5 postcard with photography from Keith Pattison (see one story below) and circulated to day care services, community centre, libraries and older people's organisations.

Evaluation of the partnership project showed a positive impact on older people with dementia: staff reported that many of the older people were more vocal and more engaged during the writing project than in other activities.

When the project ended with a discussion between writers and scientists in front of large audience at Live Theatre, the scientists acknowledged the positive role of creative writing and the arts in explaining dementia to the wider public. This partnership between scientists and writers led to a greater awareness of dementia in the general public through the wide coverage in regional media and the three literary outcomes. Hopefully this will result in people with dementia being treated with respect and humour, not disapproval and embarrassment.

### **The Hospital Project**

Following the production of the *Dementia Dilemmas* flash fiction, I was approached by senior staff at Northumberland, Tyne and Wear NHS Foundation Trust who were impressed by the impact of these postcard-sized stories. Subsequently, I have been commissioned as Writer-in-Residence with their Dementia Services. The main aim of this project is to use creative writing with dementia patients to encourage communication and self expression, to bring calm and concentration and to reduce the isolation created by dementia.

For one session each week, I spend time with individuals or small groups using pictures, objects, poems, conversation to encourage creative and lively responses. After I have captured their words, I transcribe and edit the outcome

into poetry or life stories. I particularly like to use the Malaysian poetic form 'pantoum' as this has a rhythmic format which reflects the repetitive speech patterns of dementia. Sometimes, I can add photos or other artwork to an individual's piece of writing which they can take home, reminding relatives that the person is more than the medical condition of dementia. A final project exhibition in December will demonstrate that people with dementia can make a contribution to the cultural life of the region and challenge the stereotype that they are solely a drain on the public purse.

### **What can a writer learn from people with dementia?**

My own personal development as a writer has benefited from both these projects. Fiction writers are often asked about their sources of inspiration; I soon found an idea for a dystopian fiction arising from a conversation with an older woman in the day centre, as recorded below:

*On my first morning at the dementia day centre, there were about twelve women sitting quietly in the main room having coffee and biscuits. Betty, aged 83 was sitting next to me. She pointed to the circle of women and said*

*'Look at that. Have you ever seen a group of women so quiet?'*

*I explained they had all just been brought in by mini-bus, as had Betty herself, they were having coffee before the mornings activities began. Betty repeated*

*'Have you ever seen a group of women so quiet?'*

*Then turned to me and said*

*'Somebody must have given them GLUE.'*

*If the media headlines are to be believed, older people with dementia are a drain on the tax payer and a burden on society which fed into my Atwood-esque response. As I pondered the role of the novelist in this dementia writing project, I imagined a dystopian fiction where the politicians, the economists and the scientists all collude to silence the frail, the old and the demented with GLUE stirred into their coffee.*

### **How did this project differ from a generic creative writing workshop?**

Using the same approach that I would take with any creative writing workshop for beginners, I used prompts including pictures, music, objects, poems, stories. For example, I developed a card game with a question on each card, some encouraged long term memory and others aimed to elicit attitudes and opinions. e.g. *Tell me about your best ever fish and chips*

Or

*What would you do if you were Prime Minister for the day?*

or others which might not have been part of the older people's 'normal' conversations.

e.g. *'Water? Air? Fire? Earth? Which one are you?'*

I expected the response to be lack of understanding but in fact there was a really interesting conversation which ended

*'Fire. I've always been fiery and I always will be FIRE.'*

Both projects have given me an opportunity to reflect on the role of writer in participatory practice. I found that unlike a generic workshop, where the participant is usually holding the pen in their own hand, there was obviously a much greater level of intervention in the actual writing process.

In the first project, I was commissioned to create a literary outcome based on conversations, to some extent I felt I was using a different writing 'voice' in order to edit some of the conversations with older people, trying to raise awareness about dementia whilst keeping a positive image of dementia sufferers. However, in the second project, I am recording the individual's actual words and shaping them into poetry or life writing

In both cases it is the skills and creativity of the writer that finds ways of using the words spoken by the person with dementia. If we are keeping participants at the heart of the project, not writing FOR them but writing WITH them, then it begs the question *'Whose writing is this?'* For me, the answer comes when I read a piece of writing back to the person with dementia who spoke those actual words, seeing her delight as she responds - *'THAT'S ME.'*

# Playing Away

Aye, it was a good match but I miss having a beer with Jimmy and the lads after the game. All dead long ago.

'Watch out, Grandad, you're going the wrong way up the escalator.'

Eh? Been on the Metro to every match.

They must have changed the signs.

Don't remember it being this busy before.

Smells as if someone's been sick.

So many people with things in their ears, are they all deaf?

I'll follow the black and white shirts; Newcastle United fans have always been canny. Getting out here, thank goodness.

But this isn't Byker.

'Sir, you need your ticket to get through the barrier.'

Where's my wallet? I keep losing things since Maggie passed away.

'This is Gateshead, sir. You'll need a ticket to get back on the Metro.'

My head is all fuzzy. What was it the doctor said? That D word.

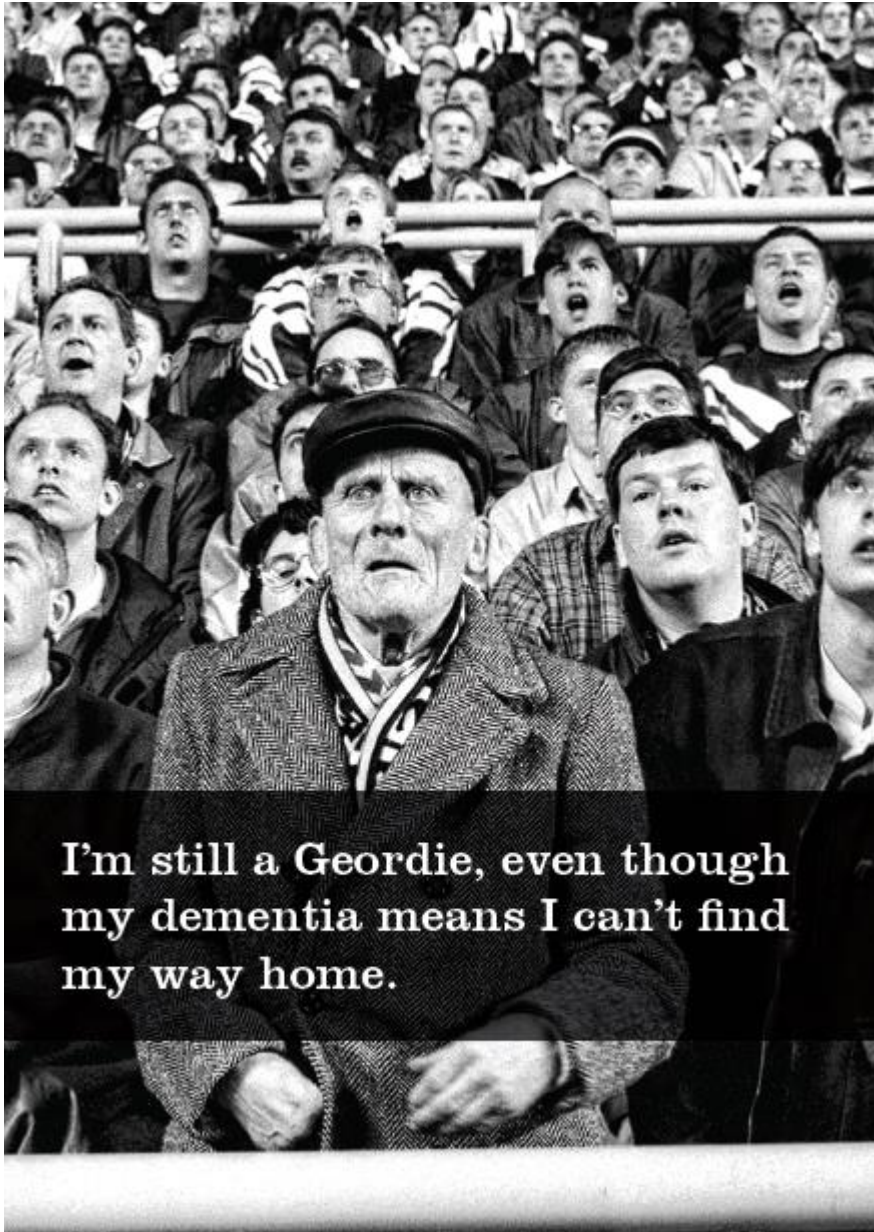
'Sir? Is there someone I can call?'

Hey, don't touch my bad arm. Get off me.

Why's she calling the police? I've done nothing wrong.

Worked all my life on the Tyne. Never had any trouble.

It's just not right.



I'm still a Geordie, even though  
my dementia means I can't find  
my way home.