

## **Bringing Writing, Water and People with Dementia Together**

**by Caroline Brown**

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### **Background**

As part of the 2017/2018 Words Work Well for All project, a programme of creative writing, storytelling and visual arts activities with people with long term health conditions in Glasgow to promote wellbeing, we explored the possibility of offering the established Water Story\* health and wellbeing benefits to people affected by dementia, those living with dementia and their paid and unpaid carers. \*Water Story sessions take place on the water, mainly on board the Peccadillo Barge as it cruises through Maryhill along the Forth & Clyde Canal but also on Loch Lomond.

Despite many challenges (to be outlined later) we found that passengers with dementia were animated, engaged and delighted to reminisce, to write about their lived experiences on the water. There were facial expressions of joy, much laughter and some moving interactions when their pieces were read back to them. Determination to take part in a boat voyage often overcame physical obstacles. At the start of one windy, wet sail on Loch Lomond, one lady, who used a zimmer, was so determined to get onto the boat that she 'bumped' herself onto the boat on her bottom.

Carers reported that a boat trip, either scheduled or in the past, proved more memorable than other current events in the life of the person with dementia. Ultimately, very few such trips went ahead, but even this small exploration revealed benefits that exceeded all our expectations.

### **Benefits**

- unique experience for those who often live with a lot of stress
- promotion of memories and inspiration for people affected by dementia
- sharing by carer and person affected by dementia of both the boat experience and telling of life stories
- adventure overcomes fear
- networking opportunities
- social interaction, inclusion and connectivity
- enthusiasm from care homes who are constantly seeking events for residents/attendees
- empowerment of people affected by dementia who are as capable of telling their stories as anyone else
- being "seen" – both carers and their charges
- unpaid carers can do their own writing and not be a 'carer' for a period of time, rather enjoying a beautiful unique experience with a loved one

- potential to produce a book of stories with photographs of individuals

### **Written example, scribed by a Thistleknowes carer on a Loch Lomond trip:**

#### **When I was on the water - by R.**

*I was about seasick*

*It smelt nice on the water.*

*I could smell the pines on the surrounding tress.*

*I felt seasick with the choppy water.*

*I was cold, freezing, foonert.*

*I used to go to the river Garnock fishing, angling on the banking trout.*

*I don't eat fish, I just like to catch them and feed them to the neighbour.*

*I used to fish for salmon in the river with a worm.*

*I caught a 2lb one, but the biggest one I poached was 12lb.*

*At about 12 years old, I fell in the water, the wee lock boat had a hole in the bottom.*

*There were 6 of us in it.*

*It was new year's day.*

*There was no one around.*

#### **Challenges / Obstacles**

The vessel that is in Glasgow and mostly available for Water Story sessions is a wide beam canal boat on the Forth & Clyde Canal. Legal limit of passenger numbers on this boat is 12, plus two crew. There is no disabled access and boarding the vessel involves stepping from the quay to the gunnel (over a gap with water) and then four deep steps. The door lintel necessitates a stoop on entering and the space inside the barge is, obviously, limited. Bathroom facilities include a portapotti that is quite low and not fixed to the floor. Heating is not available when the vessel is underway (woodstove cannot be lit).

Immediate obstacles were clear, excluding anyone with serious mobility issues or wheelchairs. A vessel of this size simply doesn't have the capacity to make the necessary adaptations for wheelchairs and a decision was made to continue the project with people who could walk well. However the step over water and unfamiliar space seemed to cause alarm, even to the more mobile passengers. Interior issues such as handrails for the toilet and padded lintels at low points on the roof are more easily addressed, but any boat project involving people affected by dementia will have to pay careful attention to the fear of accessing a vessel.

The most debilitating obstacle was cancellation. A project of this size has limited resources to set up trips, and, in this case, numbers of attendees are severely restricted by the barge capacity. Each person with dementia will have a carer and this means that an absolute maximum of 5 (more comfortably 4) people with dementia can be booked on for any session.

The booking and arrangement for each session calls for complex planning that takes time and administration. However, these people and their carers are sorely challenged with health issues and, despite the best intentions, may have to cancel at the last minute. In the case of care homes, this will often mean that the whole group is unable to attend. A project the size of Water Story simply cannot absorb the cost of rescheduling a cancelled session - the small scale of the project is a fatal compromise here.

### **What we learned**

Valuable learning was drawn from the above challenges and other unpredictable considerations:

- access to a vessel must always be carefully risk assessed
- unfamiliar interiors/comfort need assessed
- boat safety procedures need particular communication as there are individuals who will be responsible for others (who may not remember announcements) as well as themselves
- large enough vessel and schedule capacity is needed to absorb cancellations
- arrangements for scribes must be made if carers are unwilling to be the scribe (they can benefit from doing their own creative writing)
- care homes are eager to take advantage of opportunities like this but liaison and planning can be time consuming
- exclusion of care home residents on the grounds of physical disability can cause discontent (e.g. saying that only non-wheelchair users can go on the trip)
- in the event of publicity or publication of writing/images, there can be complex issues regarding consent
- time must be given to support people appropriately so that they don't feel rushed
- full focus needs to be on the group – it cannot be combined with other writers or the public
- facilitation must be flexible enough to assimilate unpredictable behaviours of people with dementia

We have garnered invaluable experience on this project, even though the obstacles brought it to a premature halt. We hope to carry this learning forward and would be happy to advise anyone who might be considering a similar project.

To succeed in getting a dementia-related writing project onto the water, we recommend partnership with established organisations like the Seagull Trust or Cruise Loch Lomond. The latter does not, as yet, have disabled access on any vessels but they do hope to achieve that in the future. They have also been in conversation with Lomond and Trossachs National parks to ensure that piers around Loch Lomond are wheelchair accessible. Conversations beyond the Water Story project reveal that this could benefit disabled people across the country.

Seagull Trust on the other hand has been offering trips to disabled people for many years. They have vessels in Kirkintilloch, Falkirk and Livingston and expressed an interest in our project during a brief discussion. It is interesting to note that they are also continually challenged by cancellations, but have developed a system whereby their vessel capacity and regularity of sailing schedules absorbs the impact of cancellations. Unfortunately the Kirkintilloch boats (that serve Glasgow) are hugely oversubscribed, but they do have capacity in Falkirk which is just a 40 minute drive from Glasgow.