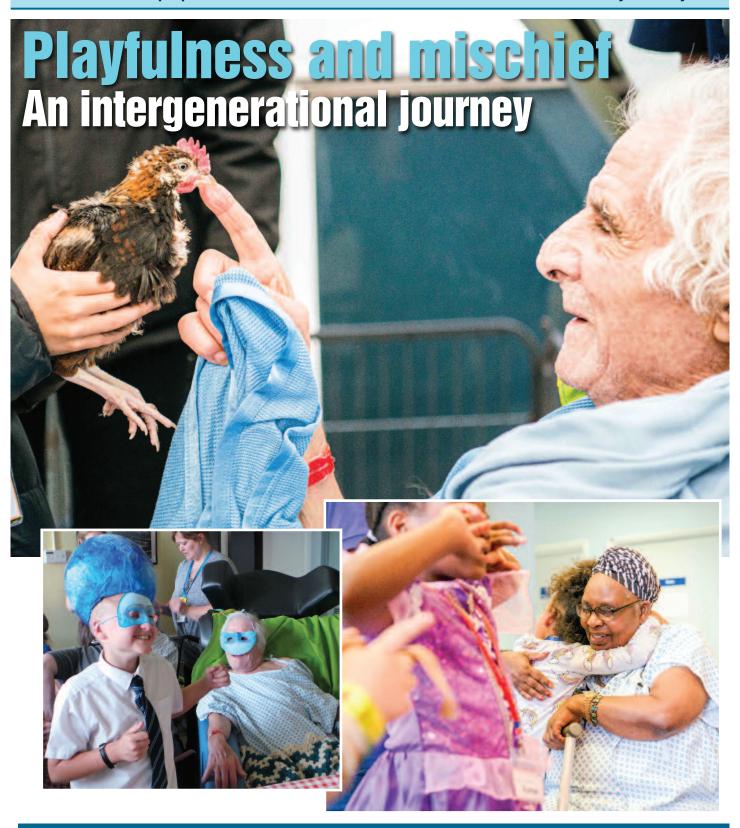
## The Journal of DementiaCare

For all who work with people with dementia

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- **Also inside** | **-** How 'gay bashing' in the past can affect people now
  - Rare dementia support Gaming for awareness

# DementiaCare Inside

For all who work with people with dementia

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Cover photographs: Sincere thanks to photographers Akiko du Pont and Jo James, and to all involved in the work described on pp22-25.







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# Playfulness and mischief – an intergenerational journey

*Jo James is consultant* nurse for dementia and delirium, Imperial College Healthcare NHS Trust, Dr Nicola Abraham is lecturer, Applied Theatre, Royal Central School of Speech and Drama, and Dr Elizabeth McGeorge is a junior doctor who was intergenerational fellow.

Photographs by Akiko Du Pont (akiko-dupont.com) and Jo James.

An intergenerational Christmas party held on an acute hospital ward sparked off plans for a whole new project. But would it be possible to overcome staff resistance? Jo James, Nicola Abraham and Elizabeth McGeorge describe what happened next



hen we first had the idea of holding an intergenerational Christmas party on an acute ward with patients who had dementia, we soon ran into organisational problems. Initially, our idea was simple: our hospital dementia team would provide the patients, the paediatric team would provide the children, and the Royal Central School of Speech and Drama, our partners, would provide the expertise in facilitating multi-generational events.

But we quickly discovered that we could not match the paediatric inpatients with the adults on our ward as there were too many variables and the children's hospital length of stay was too short. Instead we turned to a school, chosen because one of the teachers there was related to one of our doctors.

Held three years ago, our Christmas party was a great success and marked the start of a unique collaboration between local schools, the hospital and the drama school. We were spurred on not just by our own success but by experience elsewhere.

We had heard about intergenerational events in care home settings with evidence suggesting that they are mutually beneficial to residents and children, fostering empathy and respect and challenging stereotypes (Hutchinson & Webb 1988). And we had also heard of the outstanding programme at Nightingale Hammerson, which placed a nursery in their London care home. We were convinced that it would work in a hospital,

but we were beset with doubts and anxieties about how to make it happen.

We knew what we did not want: a line of embarrassed children singing a song in front of a line of equally embarrassed adults. We wanted fun, mischief and joint endeavours, something that would make us all laugh and something that would alleviate the crushing boredom and isolation of a hospital admission for a person living with dementia.

### **Protective responses**

Despite the evidence in favour of our plans, the reactions of our colleagues made us doubt ourselves. One of the early responses from a member of the paediatric staff was "I wouldn't let my children go to something like that." It turned out that this view was based on a concern about exposing her children to the unpredictable behaviour of the patients, mirrored by a member of the dementia team who was worried about exposing her patients to the unpredictable behaviour of the children!

This protectiveness persisted on both sides throughout the project, but we challenged it and rightly so. After more than 60 events involving over 180 patients and 130 children, we can confirm that, if there was any unpredictable behaviour, it was greeted with amusement and tolerance and never upset anyone. If anything, it created more joy.

Ward (24hrs before) Go ahead given by infection control Safe space to run the event Staff aware and happy to proceed

Patients (same day) Assessed by the Fellow Want to come Clinically stable enough to attend No developing infection or unexplained temperature

**Pupils and Teachers** provided with children's health checklist Children have had teaching on handwashing, dementia and hospitals



Following our intergenerational Christmas party, we secured a two-year grant from the Imperial Health Charity for the new post of "intergenerational fellow". We had two fellows in succession, both doctors - Charlotte Lance and Elizabeth McGeorge (co-author) - whose role was to be a project manager and ensure that the programme was delivered safely for patients and children.

Other doctors from Connecting Care for Children, our NHS trust's scheme for integrating paediatric care across north-west London, joined us for specific events and gained unique insights from being part of them. As one of them said:

I mean, it was just amazing... it was very rewarding to care for people without being clinical, to help them enjoy their quality of life. Maybe one day it could be part of our jobs to spend a couple of hours with patients and watch them enjoy doing something.

#### **Setting up**

Setting up a project rather than a single event brought additional complexities. Local schools had to be approached, four of which agreed to take part by involving children across the 7-11 years age range. Wards with space suitable to host larger groups including young children had to be identified. And, finally, there was our infection control department, who were remarkably open and supportive, and developed a system to keep both sides safe (see diagram above).

Everyone had to agree to the infection control system and accept that an event could be cancelled at short notice if any of the criteria were not met. The system worked well as it kept our events safe, although it did mean that there were occasions when we had to rearrange venues or even call off an event altogether.

The schools wanted to embed the hospital events into their curriculum, which meant that we had to find enough activities to cover multiple sessions every term. We wanted to provide variety and stimulation for both the adults and children. We tried a range of activities with different facilitators from the Royal Central School of Speech and Drama and elsewhere, who were all instructed to make the workshops about coproduction and partnership working. Activities ranged from drama, dancing and poetry workshops, arts and crafts, team challenges, gardening and museum outreach to a farm visit and puppet-making.

Over the two-year grant period we worked with 12 different facilitators and learned what did and did not work together. The project became a journey for the facilitators too as they learned how to navigate the complex interplay between the environment, patients, staff and children.

Some facilitators started with a set plan and tried to adhere to it, but as time went on most realised that things rarely turned out the way they expected. One told us that delivering sessions was about "having a jumping off point and not knowing where you are going to land and being fine with that," while another said "you can learn from every session and always be improving, but just leave your ego at the door and just let people respond in the way they want to respond."

We discovered that patients felt uncomfortable if they were too exposed in an activity or were asked too many questions. Sometimes, they simply enjoyed being there and watching. We also found that, particularly on hot days, the children preferred quiet, contemplative activities. Whatever the activity, both adults and children loved creating things and being able to take away the fruits of their creativity. As one of our physiotherapists put it:

It's a really nice talking point, I've seen people talk to their families about [artefacts from the workshops] or we can use them in therapy sessions to say "what did you do?" and it engages them.

One of the challenges of the project was persuading patients to come. Sessions had to be held in the early afternoon and patients who had agreed to take part in the morning might be too tired or sleepy when the time came. Sometimes, most of the patients were too unwell to come. If numbers were too low, staff or helpers would join in more with the activities.

We came to take the variation in numbers in our stride. It is what happens in an acute setting and as one consultant geriatrician said, we needed to "stop worrying about numbers and think about the impact it is having on the people who are there."

It is a given that children are playful and that many will also be mischievous. However, playfulness and mischief in an older adult, particularly one living with dementia, is often distrusted or misinterpreted as due to cognitive impairment. In fact, playfulness in older adults is associated with better health (Yarnal & Mitas >

Above: the infection control process Left: A collage-making session

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The project promoted empathy in the children. After they had been coming for a term, some would take responsibility for helping patients who needed support without being prompted

clowning and teasing are core components of this playfulness

(Yarnal & Qian 2011). The more extreme the behaviour, we found, the greater the connection between adult and child.

A teacher from one of our partner schools saw it this way:

There was a wonderful elderly lady telling about some romantic tryst on the Serpentine that was hysterical... We are always, particularly as teachers but also adults in general, we are very careful around kids and very appropriate and very whatever, and it's wonderful because the older people have none of that. And it's nice, it's more natural, like it's a sort of in a way more the way it should be, so it's more direct. I think it was nice because it surprised the kids and helped them let down some of their barriers.

Patients let down their barriers too. Children who had been described as "challenging" formed some of the closest and most meaningful friendships with the patients. The patients also responded more positively to children who did not follow instructions or became very excited. One patient told us that he "loved the energy".

### Research and evidence

As is often the case in health care, our grant was awarded on the basis we would provide evidence that the intervention was effective in the hospital setting. To meet this requirement, we wanted to research the impact of our intergenerational project on patients, children and staff, focussing on mood and levels of enjoyment for the patients and attitude, enjoyment and learning for the children.

But when we applied for NHS ethical approval,

what had at first been a small part of a largely practical project soon became the biggest and most complicated logistical challenge that we were to face. The application process is highly rigorous because weighted towards medical research, but it was hard to apply that rigour to what we wanted to do, namely to ask patients if they had had a good time. Eventually, we had to abandon the idea of asking our patients anything.

Instead, we concentrated on the children, facilitators and staff, which gave us some excellent insights. We had fallen into a trap of believing that we needed a medical-style evidence base to justify something that was really about fun and joy. This is common in health care but will have to change if there is to be more emphasis on social prescribing and interventions to promote wellbeing in future.

### **Project outcomes**

Although we had to exclude patients from our formal evaluation, we were able to collect informal feedback from them. A female patient wrote: "Thank you for making my pain disappear for the afternoon" and another stated "I can't think of anything more uplifting than seeing children."

One of the ways in which we were able to measure impact was through our photographs of the events. We were lucky to be supported by Akiko Du Pont, a documentary photographer who chronicled our journey, and this extraordinary record witnesses to the joy the project brought to all those who participated. Every photograph was copied and given to the patients and schools as an "album" of cherished memories.

We wanted the project to be as inclusive as possible, so we tried to engage ward staff, therapists, doctors and patients' families. A facilitator noted:

What's been really lovely is having the staff take part as well, having continuity of staff and nurses we recognise. [Nurses] that knew the patients and also would join in... So they weren't just sat watching or just in their role but they were actually participants as well and I think that put everyone at the same level and made it a really, truly intergenerational experience.

Ward staff were reluctant at first, but eventually started dropping in to spend a little time in the sessions and began to look forward to them. The matron commented:

When the kids are here it has a positive impact on the ward. We look forward to Wednesdays because we know on a Wednesday the children are coming and patients are excited about it, it is something to look forward to.

Our research with 75 of the children was facilitated through informal drama-based focus groups, which canvassed ideas before and after the children had been through the programme. The changes in attitude and approach were dramatic. When asked after the project, one child said, "I learned how to take care of older people and what they like to do... I always ask what they'd like to play or how they are feeling or what they want to make." Another said that one should always "speak kindly and clearly."

A teacher observed that the project promoted empathy in the children. After they had been coming for a term, some of them would take responsibility for helping patients who needed support without being prompted. For example, when we were visited by a farm, two children put down the animals they were holding to help a patient who had just arrived. "Quick, get Theo an animal!" one of them called out to the facilitator.

Parents observed changes in their children too. They were given questionnaires, in which we received comments such as the following from three separate parents:

My daughter always looked forward to hospital

visits, she seemed to have learned more about people with dementia, being compassionate and helping others.

My child enjoyed participating and was always excited when visiting. Furthermore, he has developed his speaking and communicating skills.

[My child] is more aware of needs of elderly, she is able to relate better especially as my grandmother has dementia. She has thoroughly enjoyed this experience and I love that she was able to take part.

### Conclusion

In the two years of this project, we have learned an enormous amount.

It has convinced us that this approach has value not just to the children and the patients but to everyone involved. It was more complicated than expected; we had to learn to be flexible (not a natural position for hospitals or schools) and change what we were doing at the last minute if necessary.

All of us had our preconceived notions about people with dementia and children challenged at different points. We did not expect to find ourselves part of a diverse and caring community made up of patients, artists, performers, doctors, nurses and children, but that is what happened and that is what made the programme "fantastico" as one participant expressed it.

In March, we had to stop the programme abruptly because of the pandemic and we are currently faced with finding a new way to deliver it in the hospital. We believe it is needed now more than ever. Hospital stays have become more frightening and patients more disconnected and isolated.

So we are continuing to connect our patients and children in schools, but we are doing so remotely, using teachers as facilitators in schools and staff as facilitators in hospital. Life stories, storytelling and digital letters are the creative basis of this joint endeavour by patients and children. It is not quite the same as meeting face-to-face, but it continues to be well worth doing. Less mischief, perhaps, but still plenty of fun.

