

Taking the isolation out of isolation

PETER MCINTYRE

The isolation that is essential to the physical health of people undergoing stem cell transplantation can be terrible for their mental health at a time of great stress. Patients are giving the thumbs up to a novel way of staying connected.

Leukaemia patients who undergo stem cell transplants spend four to six weeks in an air-filtered sterile room, with limited human contact and little stimulation. Facing a life-threatening disease and arduous treatment, they can become isolated and depressed.

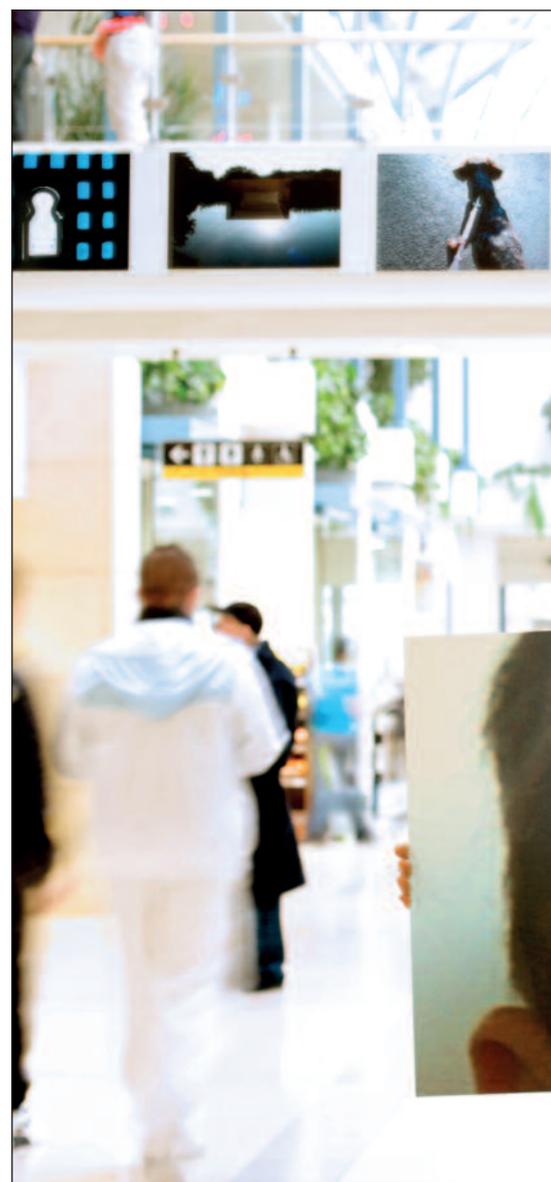
St James's Hospital in Dublin hosts Ireland's National Stem Cell Transplant Centre, and when it developed a new 21-suite state-of-the-art unit in the year 2000, Shaun McCann, then professor of haematology, worried about the emotional effect of the environment on patients.

McCann punctures a few Celtic

myths about the 'fair city'. "St James's is not in the most salubrious area in Dublin. The transplant unit (then the National Bone Marrow Transplant Centre) is near the Guinness brewery, and the ground floor rooms have a choice of view of air-conditioning pipes, blocks of flats [apartments] or perhaps barbed wire.

"I wrestled for a number of years with how to connect them to the outside world so they would not feel that sense of stress."

In 2001, he met Denis Roche, a musician and artist who was working on a project to do with connectivity through music and art in a unit set up



by the Massachusetts Institute of Technology (MIT) in Dublin. During their meetings, Roche came up with the idea of creating a virtual window in patients' rooms and projecting images onto them. McCann recalls, "The idea that we could create a virtual window that would connect them with the outside world, and we could introduce all sorts of different images, seemed to me like a very clever idea."



ment, and himself an artist, was keen to help. After detailed negotiation with the hospital infection control team and hospital managers, they introduced Open Window into the unit.

Patients control the images themselves from nine channels, which include traditional or classical art (Van Gogh's *Sunflowers* for example), art works contributed by contemporary Irish artists, and videos with soundscapes, as well as material they could generate by asking for a webcam to be set up at a chosen location or by giving a mobile camera phone (donated by Vodafone) to a friend or relative.

Although there is a centuries-old tradition of art being used in healing, there are precious few trials to test the effect, and those that have been done are small and rarely rigorous. McCann saw a chance to conduct a proper clinical trial to assess whether using images can improve quality of life by reducing patients' anxiety, depression and stress.

Using a psycho-oncology grant from the Irish Cancer Society, McCann recruited Catherine McCabe from the School of Nursing at Trinity College, Dublin, to run a prospective randomised trial.

Between 2006 and 2009, 180 patients with leukaemia completed treatment in the trial, 84 of them being cared for in an Open Window room and the other 96 in rooms with no extra visual stimulation. The severity of their conditions can be judged by the fact that, of the 199 patients originally randomised to the trial, 12 died and seven withdrew after their conditions deteriorated.

One important benefit of Open

Open Window. Katie Verling in the foyer of the St James's National Stem Cell Transplant centre, with one of the images contributed to the arts project that she says helped save her sanity during five weeks spent in isolation

Roche developed a computer-based system that enabled a projector to throw a large picture onto the blank white wall of a room. Fran Hegerty, a physicist responsible for keeping St James's ITU equip-

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Window, notes Shaun McCann, is that it gives patients autonomy. “One patient said it was like having a private art gallery. The image was totally controlled by the individual and they could choose music, pictures, videos, pictures of their families etc. They could go back and look at the same image. They also had a television, but most people who are very ill do not watch television.”

Patients in the Open Window group showed significantly lower levels of anxiety on the day before the transplant took place, compared with the control group, and significantly lower levels of depression before the transplant. There were reduced levels of anxiety and depression at other time points, but these were not statistically significant. There were no differences between the two groups in levels of distress.

As well as scoring for depression and anxiety, Catherine McCabe carried out semi-structured interviews to provide additional insight. Notably, patients in the Open Window group were more than twice as likely as patients in the control group to report that the experience of cell transplantation was better or much better than expected (63% against 27%).

In other respects the groups were similar – indeed the study highlighted how patients in both groups undergoing this life-threatening experience had a changed perspective on life and friends, and expressed surprise that they had coped so well.

Finding the images

Curator Denis Roche started by spending time with the patients. “I posed a

question: ‘If there was any image you wanted to see on the wall, what would it be?’ They would mention a location or a person, and we would talk about that. I had to understand the thoughts people were having about what was happening to them, being ill in this room. They spoke about it as a bit of time out of life.”

With support from the Arts Council of Ireland, he approached artists who were interested in themes that seemed to fit, resulting in a variety of images, including contemporary and video-based art.

Artist Cathy Fitzgerald had been to visit the ward and understood how isolated patients would feel. “I thought that I would go spare if I had to go through that without being able to look out of the window and see some greenery.” She took photos that followed her daily walk. “I had my dog Holly on a lead and one of the high-powered Nokia phone cameras in the other hand, on a walk in a little lane under Mount Leinster in County Carlow. Catherine McCabe told me that many patients thought the pictures were of their own area. It seemed to give them a lot of respite.”

Patients in isolation

Katie Verling ran an arts venue in Limerick before she was admitted to St James’s five years ago with leukaemia. She contrasts the time she spent in the isolation ward during her chemotherapy treatment with the five weeks she spent in the ward with Open Window during her bone marrow transplantation.

“When I was diagnosed, I was

brought to Dublin in an ambulance and was immediately put into one of the rooms in the isolation ward. It is total deprivation without any sensory stimulus. You are in a room with white walls, blue doors and your own bathroom and a kind of ante room with a kind of vacuum system so you hear no sounds, you get no smells and there is nothing to look at.

“You can’t put anything on the walls. You have nothing familiar around you. When people come to see you they wear plastic and can’t sit on the bed. It is not appropriate for people to hug you – the nurses barely touch you. Your immunity is totally and utterly compromised.”

After several spells in isolation over a four-month period she went stir crazy. “For a day or two I was demented from the absence of colour and light and sound.”

Later when she was admitted to an Open Window room, she found the experience transforming. Her boyfriend, Tom, took the phone camera through Dublin as he walked to visit her every day. “It was December in Dublin and there were beautiful sunrises and sunsets. I saw the bridge he walked over every day and when he went back to Limerick he took photos in the market of people I know waving at me, and all those lovely things gave me a taste of the outside.

“I loved putting on a video of horses in a field by a river moving around and chewing grass in the dappled sunlight – it was so relaxing. There was another video of a boat going down a river, and I loved that sense of being able to travel

in the countryside in sunshine and wellbeing. It was like being in my own little cinema.”

Patient choices often reflected their rural background, and made a vital connection with the outside world.

One patient told nurses, “The fact that you look at the wall and you can see horses racing out there with a forest behind them, or lakes and boats – it takes away the feeling of being caged.”

Another said, “That video with the

cows grazing. I mean being born and reared in the country I felt I was in that field.”

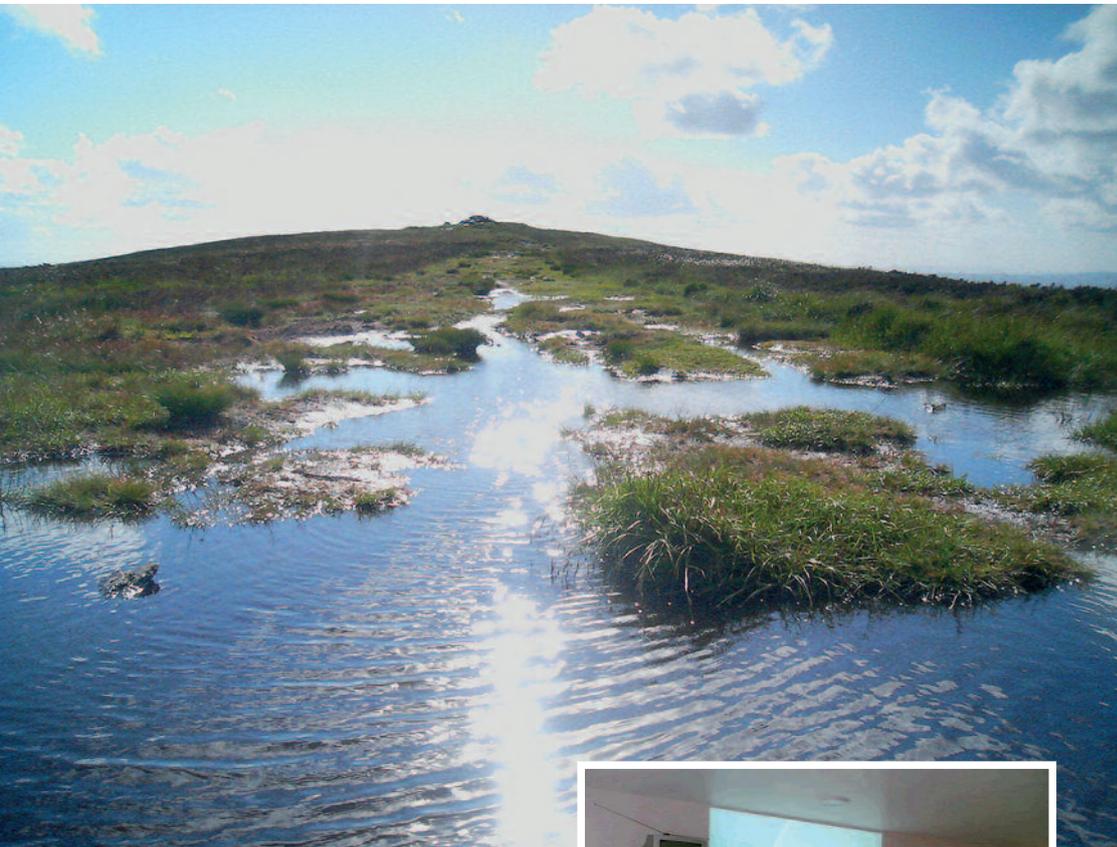
Catherine McCabe recalls that one young man asked for the webcam to be put in his local park. “He said that was where he would go when he was recovering, and he imagined himself being able to take walks around the park again. It was like a personal goal.”

Not everyone wanted nature. One 18-year-old woman was especially happy when her sister took the mobile phone to her college and sent pictures back to her.

Surprisingly, perhaps, there was limited demand for pictures from home, as for some this could be distressing.

Even if patients did not like what they were seeing, it gave them a talking point. Catherine McCabe said, “I am not an artist and at the beginning I thought this is not working; they don’t like it. I came to realise that they were doing what anybody would do in a gallery. They could look at what they liked, when they liked, and they felt they were free to comment because they could control it. There was no hierarchy and nobody judging their opinion.

“One of the images coming in was from Dun Laoghaire, one of the main ports here. That is lovely on a summer’s day when the sailing is on, but one day I went into



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A calming influence. Patients can choose what they see through their ‘window’, from traditional or classical art, pictures contributed by contemporary Irish artists, or videos with soundscapes; they can also keep in touch with friends and family through pictures sent from a camera phone, and even watch the world go by via a webcam set up in a location of their choice



FRAN HEGERTY

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A window on the world. This image, by Paul O'Connor, is one of many contributed by Irish artists who were approached by Roche because of their interest in themes that seemed to fit

the room and it was miserable and wet and there were splashes of water on the camera. The patient was speaking to the consultant about the image and the three of us stood there for about ten minutes saying how awful it was. That was a conversation that would never have happened without Open Windows. I have numerous examples of how the nursing staff got to know things about patients that they wouldn't have.”

Shaun McCann was aware that images can be very potent, especially in Ireland. “One of the mantras I had was that we might not do any good, but we must be very careful not to do any harm.” A committee – including an artist, an art historian, a psychologist and some of the nurses – was set up to

select pictures, but this did not work too well at first.

McCann recalls, “We used to meet in a seminar room next to the unit and the discussion was extremely sterile because I was still the boss, and everyone kowtowed to me. It didn't go anywhere. Then Denis Roche designed an inflatable tent which we put as far away

as possible from the unit. When we showed the images there, the whole hierarchy broke down and everybody started talking about it. I was no longer the professor of haematology – just somebody trying to look at images.”

Where next for Open Window?

It is three years since the trial ended, and a year since the results were published in *Psycho-Oncology* (doi: 10.1002/pon.2093). Open Window is now used in St James's transplant centre as part of normal everyday care.

Denis Roche, a Research Fellow of the National College of Art & Design, is promoting Open Window to hospitals, nursing homes and individuals through his Vivartes company (www.openwindow.ie). Though currently focused on Ireland and the UK, Vivartes is also installing the system in another stem-cell transplant unit in Estonia. It currently costs about €600 to install each system into a room, day

centre or ward, but Roche hopes that the price can be brought down closer to €250 for the software and hardware. Hospitals and nursing homes pay a site licence to access the artwork, while individuals who buy the system pay a subscription of about €10 a month.

Shaun McCann, who has retired from his clinical posts, now chairs the online training unit for the European Haematology Association, and is promoting the system for other centres in Europe. “The problem is that the hospitals are all broke, even in the most wealthy countries. When you go to the CEO, he says we are buying a new oscilloscope or something, and it is very hard to argue with that.”

However, patient advocacy groups recognise the importance of this approach, he says, and he hopes to launch a campaign with the European patient advocacy group network over the coming year.

Catherine McCabe, now an assistant professor at the School of Nursing and Midwifery at Trinity College, Dublin, did her PhD thesis on the project and is putting together a grant application to evaluate its effectiveness with residents in nursing homes. “Recently Ireland published some national standards around residential care for people with dementia. I think Open Window has a role to play in meeting those standards in terms of social contact, maintaining connection with families, and in stimulation and personalised meaningful activities. We are also looking at how it will impact on people with behaviours that challenge.” ■