INTRODUCTION

In a workshop of 30 minutes, people were asked 'Why does creative work matter?' and were invited to share stories illustrating their insights. We reached a consensus that creativity engages our imagination and is therefore fundamental to our capacity for empathy. We vigorously endorsed the need for 'How To' work for introducing creative arts into hospital dementia care.

'We' were people involved with acute hospital nursing, care home management, general medical practice, occupational therapy, mental health and day services, health service development, voluntary sector organizations, informal care and creative arts practice.

As well as stories, the session generated questions, comments and strands of discussion, included here. The transcript is lightly edited from an audio-recording of the workshop, and from notes people added to a flip-chart. While some of the material is bulleted, I have reproduced stories more or less verbatim. In so doing I hope that the transcript conveys the power of people's experiences and of their willingness to be vulnerable with each other in listening, telling and questioning.

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SUMMARY

What were the key messages from this workshop?

Creativity is the exercise of the imagination, imagination is the basis of empathy and empathy is the basis of compassion. Creativity & imagination allow us to recognise and share our vulnerability in a safe place. That vulnerability is key to compassionate care.

Creativity is an essential part of the whole person - be they users or staff - it is the expression of the human imagination. We cannot afford to ignore it in ourselves or the people who use our services.

Creativity is a leveller. It reminds people of who they are. It promotes respect. It enhances humane environments.

What needs to happen now to make progress with this approach?

- **Understanding** of why creative compassion in care is important.
- **Recognition** at every organizational level that staff need support to be safely vulnerable with their feelings in order to be open to imagination and empathy.
- **Promotion and resourcing** of creative arts as a vehicle for generation of empathy and compassion in care settings.
- **Specific practical development** for acute hospital settings

What support is needed?

Effective leadership means allowing yourself to share your vulnerability with your staff and service users, to set an example as a person who values feelings and who is open to the imagination.

Value creativity in your care setting by taking a creative lead yourself, by taking time to make creative connections, by making the case for creativity with others.

Train and support staff to implement creative work. Celebrate progress, make it visible. Tell others what your team is doing. Encourage others.
Cultural Care?

Ted started us off: He was closely involved with an uncle with dementia, for whom listening to music was very important. Ted asked How much of what is important to people is available to them in the hospital or care environment?

Caro: The continuation of cultural life matters because it restores people to themselves.

Sue's story: Making Connections

I run a dementia care home, where we do art work, and there's a lot of music and singing that goes on with the staff - it's a running theme throughout the day. I'd love to do more but as the manager I'm doing all the paperwork.

One particular lady used to say a line all the time, 'as women grow old men grow cold'. I have the internet on my computer so she sat in the office one day and we found it - it's from Marilyn Munro - Diamonds Are A Girl's Best Friend. So we played it. Funnily enough I thought she'd know all the words and sing it because she kept saying that line, but she didn't sing the words and that surprised me.

That was a moment of creativity - we had a connection as we sat there at the computer and found the song, and I suppose in my daily work there's probably connections that go on like that with thirty-four people all the time. It's just taking the time to make sure you make those connections because they are important.

Ted: This is particularly true in a hospital environment, when a person has dementia.

What do they turn to for comfort? What is available to them?
Sonja:

'It might depend on the hospital - I work for a mental health trust, and in our hospital music - Singing for Health & Happiness based on the Singing for the Brain programme - is quite a regular thing. We also have Music Therapists coming in, we have Reminiscence which often revolves around music, we've even got Musical Bingo. Quite often there's a piano and there's musical instruments, so I think what's available varies between hospital settings.

Ann's story: Oranges and Lemons

One of the good things about music is that you carry your instruments with you - that is, your selves, your memories. There's hundreds of things we can do with music as long as we feel empowered to do it.

When was the last time you lot played Oranges and Lemons? The last time I played it was ten days ago and the beauty of it was that it was totally unexpected. I was doing heritage dance with a particular home which led to talk about playground games, and 'Oranges and Lemons' came up. The Activity Coordinator got a big soft rope, tied a knot in it and we improvised. We pulled it round (a circle) some of us pulled it the wrong way and that was very funny. Some got mixed up with the up and down, it didn't matter. Wherever the knot stopped - that was the person whose head got chopped. People cheated like nobody's business, we spent 10-15 minutes giggling and laughing helplessly. That for me was creativity. We could never recapture that, it's not an 'art piece', but if I remember it with pleasure and animation then I'm on exactly the same level as all the ladies and gentlemen there. That's another thing about art - it's a leveller, it's not - 'I'm the clinician, I will administer this to you' - we are level.

Creativity is

- Powerful
- Spontaneous
- Serendipitous
- Personal
- Interactive
- Fun

'Art-it's a leveller'

'what's available varies between hospital settings.'
William begins a discussion about imagination and vulnerability:

We are all here because we share a concern about dementia and people with dementia and those that care for them. Dementia is important because people with dementia are particularly vulnerable, but actually we are all vulnerable, it's just that people with dementia are a bit more vulnerable.

We all have imagination and we all have potential imaginative creativity, and I think what you were hearing in the last story had to do with people sharing an imaginative game basically. I think that what underlies creative practice - singing or dancing or playing games or writing poetry - is imagination.

I think the people who need the imagination most are the carers, the doctors, the nurses. Imagination is not high on the agenda. One of the reasons for that I suspect is because (for) people who are technically trained and expert - I'm a GP, I don't call myself an expert, but I've had lots of training in science and so on - it's easy to be scared of the imagination and much more comfortable in the 'protocol' and in the 'knowledge' and in the 'expertise'. This levelling is so important and it's important for everybody.

Sue:

I think people need to start from a feeling base. We work in a world where people are educated at certain levels and have titles, and instead of working with feelings we work with what we know, not what we feel. And if you work with what you feel first and foremost, it's a good starting point.
Compassion under pressure?

Caro: Perhaps that's where the imagination comes in, (between) feelings and what you can observe, the imagination helps make the empathic leap.

Ted: So following on from that - the big issue about care and compassion: You're pressurised, you've got a task to do, that task mustn't be interfered with, a patient's got their hand up for attention - 'I've got to complete tasks....'

If you are doing a job, are you loosing sight of the care and compassion side of it because you are doing a (pressurised) job?'

Unidentified speaker: Losing our feelings is losing ourselves.

'I feel, I fear, I get anxious, and that's me without dementia'

I care compassionately about what I do. I provide a day service for people with disabilities and people with dementia. I was being lost. I lost myself. I felt I was 'doing to' people as I was professionally paid. I went on a course about a year ago. On the course it clicked why I was so stressful: It wasn't that the job was getting too much for me, (it was that) I wasn't feeling it anymore. The pressures were driving me, and not feeling. I went back to a feeling-base, and it was like - phew! I'm back again!

'Leadership-you've got to feel it to do it'

I got back to a feeling-base because the course was about people on a journey with dementia. (But also) it was about me on a journey: I feel, I fear, I get scared, I get anxious, and that's me without dementia, so we're all the same - we all experience the same feelings. Somebody says 'I've lost my dog' and (you know) they haven't - but the feelings are real for that person. They are upset, distressed, feeling that anxiety. So it clicked. I was able to be myself and I could feel it again. It's really important, to feel it.
‘we’re all the same, we all experience the same feelings.’

We do a lot of therapy work now - laughter therapy - yes! People said ‘I'd love to go on holiday’ so we painted a scene, got foot-spa's and fans from junkshops and donations, we do sensory things - feel the water, the sand between the toes - the breeze - and it's really worked. Everybody's seen my mood has shifted. Everything’s changing. Leadership - you've got to feel it to do it.

Further points on feelings, empathy and pressure

- Feeling empathy means feeling in - and that you have to have first. It requires imagination. If you can feel in yourself, then you can be compassionate. It comes that way round.
- You've got to go on your own emotional journey to be able to be a feeling person.
- The pressures of a stressful job can cause you to lose the 'feeling bit.'
- Losing feelings then makes the job more stressful again.
- To break the cycle it is important to keep feeling and stay vulnerable.
- We need a supportive culture in order to do this.
- Creative work can help create that culture
- Creativity refreshes the imagination and helps us to reconnect with ourselves and empathize with others.
Creativity can:

- reduce isolation
- relieve stress
- aid expression
- give pleasure
- build confidence
- offer coping strategies
- benefit carers

Joe's story: The benefits of Singing for the Brain

I work in the community with Singing for the Brain. We aim the service towards people in the community as opposed to care settings, who very often become isolated. The relationship between the carer and the person they are caring for can become strained. It’s inevitable that the carer is going to become tired and frustrated and the person with dementia is not always able to communicate their feelings.

By coming along to our singing for the brain sessions they are able to experience something very pleasurable together. As well as a learning experience for both it has the therapeutic benefits.

We hear so many times that the carer can then take what they have learnt from Singing for the Brain home with them and use it within the home and carry on with the songs they've been learning and are familiar with.

It gives the carer the confidence and the imagination to do some of these more fun activities rather than constantly feeling under pressure and strain in their caring role.

Various comments follow Joe's snapshot:

How creative interaction can be effective:

- can be a good distraction technique
- aids communication - helps people get their words out
- breaks the circle sometimes, interrupts the cycle of pressure and stress
- relaxes the carer - that communicates to the person, helps keep things in proportion

'I remember quite a challenging man in a music therapy session...

... he picked up a violin and played Handel's Largo...

... He went up in our estimation.'
changes the energy, de-stresses the situation, reminds cares they can have fun, that life can be pleasant

can show someone in their talents, gifts and competence, & change the perception of others toward the person

We used the rest of our time in a discussion woven around two questions:

Julie: How do you introduce this softening ethos of creative work into acute hospitals?

Kate: How do you support people to work with empathy within the triangle of person - supporter - engagement?

Barriers:

• Acute environments, radically different From res. care & nursing homes, now regrettably lack infrastructure once available through OTs and supported volunteers.

• Acute wards have a different emphasis from residential & nursing homes, other care areas such as palliative & EOL care, MH, etc.

• Health & Safety is often perceived as a barrier, can be used as an excuse.
• Acute wards are still catching up on making environments more inclusive to people with dementia (colour contrasts, signage, etc).

• Hospital environments can be very task, routine and rule orientated, whereas creativity is about process, communication and relationship.

• Creative activity can present 'yet another demand' on stressed staff and may be experienced as disruptive.

• People can find creative work embarrassing, exposing, strange, there can be 'a fear factor' (i.e. it touches their vulnerability).

**Barrier- busters**

• PIE pilot team are introducing music on acute wards and are also using volunteers.

• Example from Devon OTs of poetry on oncology wards.

• Sometimes as a leader you have to start the change - to get the evidence that it works - to get the agreement to go ahead with it.

• If you are sent on a positive training course - argue for the sense of being able to implement what you have learned - otherwise why were you sent on the course?

• People need to understand each other's work in order to make space for it, to express their reservations and have them addressed.

• Playback Theatre can be helpful in enabling people stand back and look at what is happening in interactions and relationships - theatre practitioners improvise and enact scenes in a way that you recognize - you see yourself enacted - it's a wake up call.

• We have to be vulnerable in order to heal, without vulnerability we can't heal, and without support we can't be vulnerable.