Changing the Culture of Dementia Care Through the Arts

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“An Allergic Reaction to the Other”

The Dementia Context
Doomed from birth to death

Laurie Scott used to love travelling, singing and all things Scottish. Now she hates leaving home and spends most of her day asleep or walking in circles. Born with Down syndrome, she is dying slowly from Alzheimer’s disease. The culprit appears to be the extra chromosome that shaped her brain and body in the womb. As Anne McLroy reports, more than three-quarters of people who reach their 60s with this developmental disorder will also be afflicted with dementia. PAGE A8
http://osocio.org/message/alzheimer-s-research-uk-wants-you-to-share-this-film-about-an-orange/
Dementia is a living death for 700,000 Britons. That figure is rising sharply. Can we cope?

Dementia costs the UK £14bn a year, more than cancer, heart disease and strokes combined, and as our population ages the number of sufferers will rise. But there are constant complaints of long delays in diagnosis and a lack of proper treatment. Amelia Hill reports on an illness that ruins lives and puts a terrible burden on family and carers.
THE LONG GOOD-BYE

the BURDEN of care

THE 36 HOUR DAY

Subsumed

loss

careGIVER

A never ending funeral

trapped

Hopeless

ALONE
Consequences of the Tragedy Discourse

• Persons are dismissed and ignored
• Persons are silenced – attempts to communicate with the person stop
• Remaining abilities are not seen/overlooked
de Kooning
Woman 1950-52

de Kooning
Woman VI 1953
de Kooning
Untitled XV 1982

de Kooning
Untitled XVII 1984
Consequences of the Tragedy Discourse

- Persons are dismissed and ignored
- Persons are silenced – attempts to communicate with the person stop
- Remaining abilities are not seen/overlooked
- Persons are treated like a child/overprotected
- All behaviours are viewed as symptoms of the disease
- Persons and their actions are labeled, categorised and judged
Public Use of Whiteboards
That’s such an important thing, for people to realize that lots of times you know how we’ve always been labeled as being violent or reacting inappropriately, but if people were to think deeper than that, and see deeper than that, lots of times we’re reacting to something, there’s a trigger...Because they often joke about, I’m going to be labeled as sexually inappropriate when I get into long-term care because I can’t stand the heat and they’re all so warm, I’m going to be in there and my children already know I’m going to remove my clothing because I’m hot. And I will be labeled as sexually inappropriate, but it will be the heat.

Partner with Dementia
Consequences of the Tragedy Discourse

• Force used to control “undesirable behaviours”
• Clinical interventions and treatments the focus
• Life long and valued activities become therapy
• Boundaries in relationships established and become the focus
• Persons are treated as objects
• Persons choices not respected
• Diagnosis not disclosed to person
• Suicide seen as the only option
When you change the way you look at things the things you look at change.
It was so uplifting to listen to these people and talk about their lives.

https://www.youtube.com/watch?v=FLcoDMbY-Q8
Emerging Colour

Dark days and tunnels
Plunging through darkness and loss
Emerging colour
Dancing with Dementia

Dancing with dementia
Embrace, enjoyment, thriving
Flow, wind and movement
I’m Still Me

Light shines through darkness
Hope shines through activism
Accept—I’m still me
Remembering Me

Circling strengths and braids
Power for persisting climbs
Remembering me
He shoots, He scores!

He shoots and he scores
Breaking away from stigma
Engaged—enabled!
Do It and It Will Be Good

Live an active life
Do it and it will be good
Light, life, warmth and love
Make Contact

Now making contact
Face to face breaking silence
Smiling be present
Opening UP to Possibilities

Surrounded by love
Possibilities beacon
My life is transformed
Possibilities...

open up our frame of reference to:
what might be possible
the potential
the promise
the capabilities
hope
Research-Based Drama

Cracked: new light on dementia

I’m Still Here
In Canada, one person in 13 over age 65 and one in three over 85 have some type of dementia.

https://www.youtube.com/watch?v=hZnLy4RJKfo
The Experience of Engaging with Research-Based Drama

Seeing Anew
The Experience of Engaging with Research-Based Drama

Connecting with Reverberating Truths
The Experience of Engaging with Research-Based Drama

Placing and Relating Self
The Experience of Engaging with Research-Based Drama

Sensing Embodied Impact
The Experience of Engaging with Research-Based Drama

Discerning Meaningful Learning and New Ways of Being
Implications of a Possibilities Discourse

• feel respected, valued and understood;
• be given meaningful choices, be actively involved in decision-making, and have their choices respected;
• feel empowered and enabled no matter where they were in the disease trajectory
• be seen as having a future and supported in continuing to thrive and in living life to the fullest until death;
• have their bodies, minds and spirits nurtured;
• remain engaged in strong interdependent, compassionate relationships and in their communities or environments as full citizens; and
• would see a life worth living
References


Thank You!

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