Dementia Awareness Starts in School

A pioneer intergenerational exchange project

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Reducing stigma

Japan (2006) - Ninchishō

Old and New Term for Dementia

Old name
“Chihō” (痴呆)
Chi (痴) : foolish and stupid
Ho (呆) : foolish and absent-minded

New name
“Ninchishō” (認知症)
Ninchi (認知) : cognition
Shō (症) : symptoms and syndrome

USA (2013) – Neurocognitive Disorder
Every Sunday, Harvard pre-med student Ryan Christ goes to a Roslindale nursing home to visit the woman he calls his mentor, an 85-year-old physician named Sofia Itkis.

Itkis advises him on everything from politics to girlfriends to careers. She tells him to make the most of his Harvard education, though she doesn’t think much of Harvard doctors. She talks about the fulfillment found in public service.

One week, though, she mentioned something Christ really took to heart. She said there were a lot of people with Alzheimer’s disease on her floor who could really use someone to talk to.

Coming from her it was particularly poignant, Christ said, since Itkis has Alzheimer’s disease herself. “I’m like, this is so meta, I can’t take it,” said Christ, an applied math major. “She has these moments of shocking lucidity
Reducing stigma

England - (2012)
Only 47% of survey respondents feel a part of their community.

When asked what they have had to stop doing, people said:

- 28% getting out of the house
- 22% exercise
- 16% transport
- 23% shopping
- 9% have had to give up everything

The opportunity for change:

- 33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- 74% think supporting people to be a part of the community would help reduce stigma.
- 47% think that dementia-friendly areas would be nicer places for everyone to live.
- 3% think that people with dementia don’t have anything to offer their communities.
- 40% think everyone has a role to play to support people with dementia in their community.

Prime Minister’s challenge on dementia:
Delivering major improvements in dementia care and research by 2015.

Source: YouGov
Anti-stigma campaigns: time to change

Michael Smith

Summary

This evaluation of the Time to Change anti-stigma campaign in England represents a milestone in international stigma research. While showing some positive outcomes, the overall picture is mixed and falls short of the wholesale shift in attitudes that is needed. A new approach is proposed for the coming decades.

If you truly want to understand something, try to change it. Kurt Lewin

Approximately 80% of respondents knew “a little” to “nothing at all” about *symptoms* of Dementia, *services* for Dementia & the different *types* of Dementia.
Awareness of Dementia in teenagers in the West Midlands

- Attitudes towards health vary considerably
- Teenagers are well-informed about healthy living
- Alcohol harm reduction message from school not robust enough
- The threat of (early onset) dementia remains remote; something that happens to others
Closing the diagnosis gap

2012 National average 44.2% (32% - 67%)

Up to 56% of people with dementia do not have a formal diagnosis.

alzheimers.org.uk/dementiamap
1. Dementia inevitable part of ageing
2. Nothing can be done
A dementia pathway that starts with accessing a diagnosis is unbalanced. Step one = tackling stigma & public awareness #AlzChat

08:30pm 19 Nov 2012
Redesigning an unbalanced pathway
Dementia Pathway

Dementia Pathway Coordinator

EARLY INTERVENTION

(A) Diagnosis
GP Assessment & Referral
Primary Care Liaison Worker

Memory Assessment
Multidisciplinary specialist clinicians.
Diagnosis: old age psychiatrist; geriatrician; Neurologist; GPwSI

(B) ‘Looking to the future’
Education, end of life care, benefits, lasting power of attorney, living wills, advanced care planning, advocacy, driving, genetic counselling, psychological services, dentistry, telehealth, hearing/sight assessments.

ONGOING PERSON & CARER CENTRED CARE

• Integrated CMHT
• Advocacy
• Respite Care
• Intermediate Care
• Crisis Intervention
• Younger Onset Dementia team
• Outpatient/Community Clinics
• Hospital Liaison team
• Planned Inpatient Admission (assessment & Continuing Care)
• Social Care
• Palliative Care
• Bereavement
• End-of-Life care
• Residential/Nursing care
• Psychological Services

Before Diagnosis

1- Prevention
2- Tackling stigma
3- Awareness starts in school
4- Emphasis on Wellbeing & preserving Mental Capital
5- Dementia Friendly Communities

Public Health, Royal Colleges, Department for Education

Person with dementia

Expert carer

http://www.westmidlands.nhs.uk/MultiProfessionalWorkforce/WorkforceSpecialists/Dementia.aspx
Dementia Awareness Starts in School

1. **Keen to know:** 25% of 18-24 year olds want to learn about dementia compared to only 15% of those over 55 years of age (YouGov, 2012)

2. **Increased exposure:** as our population ages more youngsters come into contact with dementia through family, friends, neighbours or the media.

3. **Wrong exposure:** As a result of learnt behaviour, youngsters develop a fear, avoidance or shame of the ‘D’ word.

4. **Optimum learning:** the school curriculum already supports learning about relationships and loss, illness and wellbeing, caring and compassion.

5. **The right disorder:** Dementia is an exemplar template to model intergenerational exchange, compassion, respect, dignity and to explore our capacity for caring and resilience in the face of adversity, loss and stigma.

6. **Public health:** opportunity to explore the interaction between a young person’s lifestyle, for example diet, exercise and alcohol, and the brain.
Digital Media & Self Care

http://www.nhslocal.nhs.uk/my-health/dementia

Dementia awareness starts in school

In this article...

- Why young people want to know more about dementia
- Development of an online learning unit on dementia for secondary school children

People with dementia and their carers face a lack of understanding from public services and society as a whole. Given that half of all people with dementia in the UK do not know they have the condition, they cannot get the help that they and their families need to support them with this progressive condition.

Those fortunate enough to receive a diagnosis suffer isolation and report that their friends cross the street to avoid them, and that they stop using public services, feel isolated from their local services, and are stopped by police. The Strategy for Dementia Prevention, Care, and Cure (Department of Health, 2013) sets out the 3Ps, the first of which is Prevention.

The dementia teaching module

We designed an online dementia awareness teaching unit aimed at year 8 pupils, which included input from a senior nurse. The films, lesson plans and PowerPoint presentations are freely accessible on NHS Local (pictured), our award-winning digital platform, which can be found at tinyurl.com/dementia-in-schools.

In 60 minutes, 11-year-olds should:
- Understand dementia;
- Appreciate the difficulties of being a carer;
- Understand assistive technologies and their applications.

Let’s not graduate another generation ashamed of the D – word!

•22 pioneer schools across England (10 Primary & 12 Secondary)
At Swanshurst Secondary School in Birmingham, a class of 14 year old girls are about to meet a couple coping with the devastating toll taken by dementia.

Ruby Jones was a midwife and nurse. Now she needs constant care, provided by her husband Emerson. He tells the girls how it is a 24-hour-a-day, seven-day-a-week commitment. He has to help her get dressed, remind her to eat, answer her repeated questions. Ruby herself tells the girls that the condition has totally changed their life.

This is part of a national project in schools in England to raise awareness among young people of dementia. Ruby and Emerson did their best to answer the questions posed by the girls. No one left the class room in any doubt that life after a diagnosis of dementia can be very tough for both the patient and the carer.
Dementia Awareness and Intergenerational Exchange in Schools. A Pioneer Project Contributing to Developing Dementia Friendly Communities.

“As these children grow up they’re going to be doctors, carers, working in shops, whatever it is, all of us will need to have that understanding of dementia and the community” (Co-ordinator, Gloucestershire)

“Just because a person has Dementia it does not make them an outcast. They still have feelings just like me and you” (Year 8 pupil, Newent Community School)

Teresa Atkinson
Jennifer Bray
Emerging Intergenerational Modules 2012/2013

Debating society
School Choir Visits to care homes
Singing for the Brain
Drama & Dance
Interactive IT for people with dementia
Life History story books
‘Memory Joggers’ game (maths)
Dementia Theme in Assembly
Library Service in localities to capture memories
Teaching materials
Information booklets for pupils
Pupils as dementia ambassadors
Music & Tea Party visits
Lessons: Assistive technology, dementia awareness, smart ageing
“We’ve seen schools introducing dementia into the curriculum. It’s fantastic to see the next generation thinking positively about how the condition affects people, and discovering for themselves how they can be supportive”.

Angela Rippon, OBE Alzheimer’s Society Ambassador
Ken Howard

Person Living with Younger Onset Dementia, carer for parents and an ambassador for the Alzheimer’s Society