From practice to research to policy

The Canadian Team for Healthcare Services/System Improvement in Dementia Care

- Evaluate the Quebec and Ontario (other provinces) interventions with rapid, pertinent and actionable results for key partners in order to refine the interventions
- Identify key components and key contextual factors linked with an optimal impact
- Facilitate rapid dissemination and scale up successful and sustainable collaborative care models across Canada

An Innovative Transformative Approach

Integration of research and knowledge transfer and exchange (KTE)

- *Participatory research*: stakeholders involved in defining outcome measures/feedback to sites, drawing conclusions
- *Developmental evaluation*: rapid-***as the study unfolds***- impact on health system improvement and practice
  - Rapid dissemination of innovation/best practices
  - Primarily through the ON and Qc experience (possibly others) with early input/dissemination to other Canadian provinces

Partners

- Researcher team actively engaged with 4 involved stakeholder groups:
  - Decision-makers (e.g. Ministries of health)
  - Patients/family (e.g. Alzheimer society)
  - Administrators Clinicians Industry
- Canadian Partners Council
- International advisory committee (PAHO/WHO, 4 high income, 2 middle income countries)

the Canadian perspective for innovation in health system improvement in dementia care

- Implementation projects with the perspective of scaling up by identifying key elements for rapid health system change
- Based in primary medical care closely linked and supported by to specialty care; interdisciplinary clinical leadership
- Paradigm for management of multiple chronic disease
- Training for students, residents and grad students
- True partnership: researchers, decision-makers, managers, clinicians, patient-caregiver
- Basis for ongoing Canadian and international research and policy network

For a copy of the Quebec AD report

En Français

- http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2009/09-829-01W.pdf

In English

- http://www.medicine.mcgill.ca/geriatrics/QuebecAlzheimerPlanEnglish.pdf

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CENTRE NATIONAL DE RÉFÉRENCE MALADES ALZHEIMER JEUNES

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Université de Lille 2 DROIT ET SANTÉ

Méotis RÉSEAU RÉGIONAL DE LA MÉMOIRE

French organization of care for patients with Young Onset Dementia to meet their specific needs

Florence Pasquier, M.D., Ph.D.

Alzheimer PLAN 2008 > 2012 L'ENGAGEMENT DE TOUS

Disclosures

- Participation in many pharmaceutical trials and academic studies in dementia
- Occasional participation in scientific advisory boards
- No specific disclosure for the present communication

Introduction

- **Early** or **Young Onset dementia** = usually onset before 65.
  - For some authors "**Early Onset**" means **diagnosed** before 65
  - Early dementia ≠ early onset dementia
  - "**Young Onset**" sometimes means **< 60** or even **45**

Prevalence and incidence doubles every 5 years from 35 years

Numbers depend on settings and data collection, size of the studied population; inclusion/exclusion of causes (alcohol, stroke, TBI, HD, psychosis, mental disabilities, AIDS, MS …), age < 65 years at onset, at diagnosis **or** at entry

Woodburn & Johnstone, Health Bull (Edinb) 1999,
Kelley et al Arch Neurol 2008; Harvey et al JNNP 2003

Epidemiology

- **Prevalence of YOD : 50-80** [CI95: 39-98] **per 100,000 inhab.** < 65 y. Incidence : **10-15 new cases per 100,000 inhab. /y;** As many men as women

- **Extrapolation of number of YOD patients in UK** for a population of 59 millions inhabitants: **18,319** [CI 95%: 15,296 – 21,758]

Alzheimer's disease	6,000 [4,254-7,989] 550 new cases/y
Vascular dementia	3,000 [1,832-4,526]
Frontotemporal dementia	2,500 [1,502-4,008] 460 new cases/y
Alcoholic dementia	2,200 [1,290-3,654]

Mercy et al Neurology 2008; Ikejima et al, Stroke 2009;
Ratnavalli et al, Neurology 2012; Harvey et al, JNNP 2003;
Vieira et al, Clin Pract Epidemiol Ment Helath 2013; Sanchez-Abraham et al, Neurologia 2014
Lambert et al, Eur J Neurol 2014; Ikejima et al, Psychiatr Clin Neurosci 2014

Progression and survival of patients with YOD

- Shorter survival in some old studies
- Actually more rapid decline in young than in old demented patients although no difference in MMSE score at first visit (because of delayed diagnosis and cognitive reserve?) but longer survival.
- Longer survival (except for genetic cases) **but higher impact of the disease on mortality in young patients**

Koedam et al, Dement Geriatr Cog Disord 2008; Van der Vlies Psychol Med 2009; Rountree et al, Alz Res Ther 2012, Go et al, Dement Geritr Cogn Disord 2013

Distinctive features of YOD

Delay in establishing a proper diagnosis

- Time between 1st symptoms and diagnosis 5 years versus 3 years (personal data)
- Illness often considered by the general public –and many professionals - as a disease of the elderly
- Many differential diagnosis
- Atypical features

→ difficult diagnosis → expertise mandatory

Alzheimer's Australia report 2007; Masellis et al, Alzheimers Res Ther 3013

A number of different causes of dementia

- **Degenerative** : **AD**, **FTLD**, DLB (including Parkinson), Huntington's disease…
- **Vascular** (including genetic like CADASIL)
- Autoimmune of inflammatory (MS…)
- Traumatic
- Toxic (alcohol)
- Infectious (including AIDS)
- Metabolic (including inborn errors of metabolism)
- Other

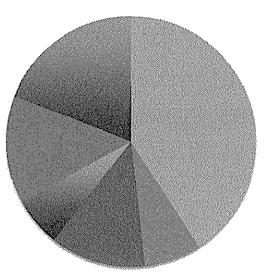
Harvey et al, JNNP 2003; Panegyre & Frencham, Am J Alz Dis Other Dement 2007; Shinagawa et al, Dement Geriatrc Cogn Disord 2007; Fujihara et al, Arq Neuropsiquiatr 2004; McMutray et al, Int J Geriatr Psychiatry 2006; Kelley et al., Arch Neurol 2008

Diagnostic distribution in the Memory clinics

Nord – Pas-de-Calais 2013 (4 millions inhabitants)
New patients with onset before 65 y =1756 out of 6497 (27%)

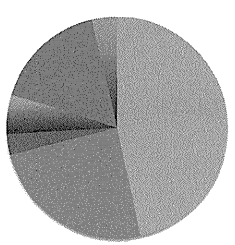
Higher proportion of related/associated disorders in young patients

New patients < 65 y
With dementia n=396 (23%)
11% of all dementias



- Alzheimer
- Alzheimer+ Vascular
- FTLD
- DLB
- Vascular dementia
- Other dementia

All new patients
With dementia n=3443 (53%)



Importance of psychiatric symptoms

- Frequent history of depression
- Apathy, Delusion, hallucinations, aggression
- **Frontal lobe syndrome** (FTLD and some EOAD)
- In addition to atypical age, and awareness of cognitive problems
  → Psychiatric misdiagnoses (depression +++ and psychosis) → diagnostic delay if no denial

Harvey et al., 1998 www.dementia.ion.ac.uk; Alzheimer's Australia report 2007; Garre-Olmo et al, Neurology 2010; van Vliet et al, Dement Geriatr Cogn Disord 2012

Atypical clinical features in YO-AD:

- **Predominant instrumental cognitive deficits :** visuospatial functions, language, praxis… disconcerting if amnesia does not seem severely impaired
- **Focal atrophies** (Primary Progressive Aphasia, Posterior Cortical Atrophy…) Rarer with ApoE4
- **Less anosognosia**
- **Genetic forms** of AD (10% vs 2%), with possible neurological symptoms e.g. spastic paraparesia, Lobar haemorrhages, extra-pyramidal symptoms

→ contribute to misleading

Imamura et al, Neuropsychologia 1998; Rossor MN et al, Lancet Neurology 2010;9: 793-806; van der Flier et al, Lancet Neurol 2011 Mendez et al, Am J Alz Dis & Other Dement 2012

Imaging

Structural imaging :

Global atrophy may be severe, but **hippocampal atrophy may be relatively less severe in young patients** compared to older patients (should not exclude the diagnosis of AD)

Frisoni et al, Brain 2007, Shibuya et al, Int J Geriatr Psychiatry 2013

However : Molecular Imaging

- FDG-PET and HmPA0- SPECT : differences according to age : more diffuse and severe hypometabolism in YOD, especially in posterior regions, posterior cingulate
- PIB-PET : no difference according to age or higher PIB retention, similar burden in posterior cortical atrophy and diffuse Alzheimer's disease

Rabinovici et al, Brain 2010; Choo et al, Am J Geriatr Psychiatry 2011; de Souza et al, Brain 2011

Cerebrospinal Fluid (CSF)

- **No difference according to age** *:*

↘ Aβ Total, ↗Tau and Phospho-Tau

even more discriminant in young patients

- No difference according to clinical features : instrumental predominance and focal atrophy or amnestic and spread

→ Young patients should be referred to tertiary centres

Bouwman et al, Neurobiol Aging 2009; Dumurgier et al, Neurobiol Dis 2013; Van de Flier et al, Lancet Neurol 2011; Moore et al, Can Fam Physician 2014

Medico-social characteristics of YOD

Caregivers of Young patients

- Observation:
  - Stunned by an unexpected diagnosis, often denied
  - « Sandwich generation »: caregivers sometimes responsible not only for their ill-spouse but also for their children, and their parents (or parents in law).
  - Often suffer from health problems
  - Exhausted, depressive, often under antidepressants and/or hypnotics
  - Have few respite
  - Anxious about heredity of the disease and end of life

Thomas et al, Int J Geriatr Psychiatr 2005; Wojtas et al, Can J Neurol Sci 2013

Caregivers of Young patients

- Main complaints:
  - **Behavioural changes** : excessive spending, addiction, impulsivity, apathy → professional, financial, social difficulties, dangerous driving, sometimes violence against spouse or children.
  - **Difficult communication.**
- Expressed needs :
  - **Early recognition and referral**
  - **Dedicated** day-care, temporary respite care or long term care facilities, and **financial support.**

Thomas et al, Int J Geriatr Psychiatr 2005; Arail et al Int J Geriatr Psy 2007
Alzheimer's Australia report 2007; Bakker et al, Am J Alz Dis & Other Dement 2010
Aramari et al AmJAlzDis & OtherDement 2012

Alzheimer PLAN 2008 > 2012 L'ENGAGEMENT DE TOUS

- Two measures of the French Alzheimer plan 2008-2012 dedicated to YOD (<60)
  - Measure 19: Setting a reference center for YOD
  - Measure 18: Accommodations for YOD

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Measure 19: Multisite Reference Centre

Call for proposal, independent international committee

- Complementarities
  - LILLE-BAILLEUL: Coordinator
    Clinic, Management, Biology (CSF, plasma): ePLM network
  - ROUEN : Genetics of monogenic forms of AD: AD network
    - National coordinator for DIAN
  - PARIS-SALPETRIERE: Imaging, rare dementias, and national FTD network
- Linked with the 26 Memory Resources and Research Centres (follow-up of patients both by MRRCs and GP ± local specialists)

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AIMS: care, management / public health, research, int. collaborat.

I - CARE

- **Raising awareness in professionals & general public**
  - Conferences, media, communications, reviews…
  - www.centre-alzheimer-jeunes.fr, http://www.alzheimer-genetique.fr
- **Improvement of diagnosis and genetic testing**
  - Identification of a **referent specialist** (neurologist) for YOD in each MRRC (n=26)
  - Continuous training, educational publications, ethics meetings (EREMA = Ethics in AD)
  - **Implementation of procedures in genetics** → 150 AD families and FTD families → DIAN GENFI, new mutations
  - In **CSF** sampling, in **imaging**
  - And in **neuropathology** AD-PATH

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II - Management

- **Identification of a referent** in each MRRC, social worker, psychologist, or nurse
- **Training of professionals** (with France Alzheimer)
  Publications for professionals, www.centre-alzheimer-jeunes.fr, http://www.alzheimer-genetique.fr
- **Support for caregivers**
  - Support groups, thematic day cares, specific programs, Week-ends for YOD patients and caregivers (UTB foundation), Web site, Brochure on YOD, Photographic work to de-stigmatize YOD and point out the specificity of different causes of dementia: "I still exist",
- **Procedures:** Mobiqual, Parcours, Long Visit (for GPs), Welcome in facilities
- **Measure 18**: Accommodations and facilities for YOD

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II - Management

- **Measure 18: Accommodations for YOD**
  - To evaluate quantitative and qualitative needs – if specificities have been detected for accommodations for young patients (< 60 years)

    To synthesize propositions

  Course of actions :
  - **Epidemiological context**
  - **National survey:** questionnaire sent to all collective accommodations possibly receiving individuals with YOD (including nursing home for people aged > 60 allowing special dispensation for younger patients) and psychiatric yards (n > 10,000)
    - Out of 2,400 young patients (<60 y) living in collective accommodations at that time, 220 suffered from ADAD

Lettre de l'observatoire n° 21 Sept2011 fondation-mederic-Alzheimer.org

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AIMS : II - Management

- **Accommodations for YOD: Course of actions**
  - **Documentary** filmed in places spotted by the survey as having an experiment in managing patient with YOD (support for raising awareness, discussion and training)
  - **Questioning:** Does the number of beds occupied by YOD patients meet the needs? Difficulties to enter such services? Inadequate offer?
    - Questionnaires analyses, visits and meetings on site (nurses, directors and practitioners), survey of services allowing dispensations, longitudinal survey of 110 YOD patients /caregivers
    - 2-day seminar with professionals experimented in caring YOD
    - 1 day meeting with YOD patients able to express their needs in public and who whished to be "actors of their life"
    - Literature analysis, other countries experience

  → Synthesis of the needs for YOD patients presented at a national meeting

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Accommodations for YOD

- **Observations and synthesis of the needs**
  - YOD specificities disconcert and worry relatives as well as professionals
  - YOD patients are scarce and dispersed in nursing homes
  - Difficult relationship between the young patient(s) and the staff (distress, painful projection)**. Need for training and support +++**
  - Before 60 y: very few patients, many with frontal lobe syndrome or severe behavioural disorders

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Accommodations for YOD

- **Observations and synthesis of the needs**
  - 3 situations needing an entry in a collective setting:
    - 1) Loss of autonomy (socially isolated or whish to protect the family) ; New needs, a lot of expectations
    - 2) "Behavioural crisis" whatever the cause (depression, delirium, inappropriate behaviour/ exhaustion of the family, social issues…) need for medical and social services, revised care plan
    - 3) Long term accommodation for severe behavioural troubles or somatic problems (difficulties with swallowing…), and too many interventions impossible at home
  - Many services already appropriate, however age was often the cause of supplementary distress
  - Limitations: focused on Alzheimer's disease and related disorders
  - Specific situation of patients with mental retardation i.e. Down syndrome

Accommodations for YOD

- **Orientations**
  - Help and support for life at home
  - Conciliate specialisation and proximity
  - Remove barriers at entry in close existing facilities willing to welcome a young patient
  - Spread care practices to all teams facing this unusual situation : role for the reference centre: running an expert network of duos (doctor + nurse) and social workers
  - A few specific accommodations for a small number of very specific patients (resource centre as well as place for training professionals from other teams) – + a few experimentations
  - Identification of facilities welcoming YOD patients: a list is available on www.centre-alzheimer-jeunes.fr and regularly updated
  - Participative training meetings, sharing of practices, regional and national once a year (project of an internet forum)

Accommodations for YOD

- **5 points to be given priority in nursing homes that welcome young patients:**
  - Need for a precise diagnosis (collaboration with tertiary memory clinics)
  - How to accompany a young patient with a frontal lobe syndrome?
  - Activities to be offered to young patients in a nursing home
  - Support to families and relatives of young patients in nursing homes
  - End of life of young patients in nursing homes

III - Research

- **Cohorts : COMAJ** (n= 270)
  - and G-MAJ, Parcours, IMAP+, AMABIO3
- **Identification of new genes, ANR on imaging**
- **Identification of risk factors**
- **Participation in studies in Social and Human Sciences** including an economic survey with Médéric Alzheimer Foundation*www.fondation-mederic-alzheimer.org/content/download/18759/83735/file/RAPPORT%20ESEMAJ%20FINAL.pdf*

IV – International collaborations

- **DIAN** Dominant Inherited Alzheimer's disease Network
- **GENFI-2 :** Genetic FTD Initiative
- **EADC** European Alzheimer's Disease Consortium
  - European Early-Onset Dementia consortium
- **ANR/FRSQ** programme**: AMAJ** Aide aux Malades Alzheimer jeunes
- **JPND** Joint Programing on Neurodegenerative Diseases
  - CSF, PPI (Patient Public Involvement)
- Task Force of the IPA (international Psychogeriatic Association)

Conclusions

- Long delay between 1st symptoms and diagnosis made at a more severe stage
- Socio-professional, family and financial impact
- Lack of specific facilities (nursing home, respite care) and trained professionals
- Genetic concerns:10% in EOAD (vs < 2% in LOAD) ; ≈ 40% in FTLD
- Important research challenge
  - Target of disease-modifying treatments, wilful population to participate in research
- **The needs of young patients of today are those of older patients in the future**

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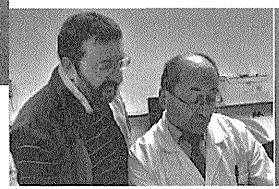
Florence Lebert

Adeline Rollin-Sillaire



Dominique Campion Didier Hannequin David Wallon

CENTRE NATIONAL DE RÉFÉRENCE MALADES ALZHEIMER JEUNES

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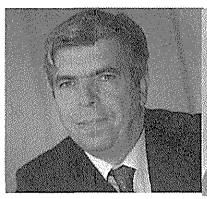

Bruno Dubois Isabelle Le Ber

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Méotis

French organization of care for patients with Young Onset Dementia

florence.pasquier@chru-lille.fr

Alzheimer PLAN 2008 > 2012 L'ENGAGEMENT DE TOUS

Advocacy for research in YOD
(and not only familial YOD)

Young patients usually:

- Have no other disease, co-morbidities, other medications
  - Especially have no (or less) vascular disorders, and cerebrovascular lesions
- Are willing to participate in research programmes, as well as their family, mainly spouse, often pro-active, well organised
  - YOD patients are actually are overrepresented in patients participating in clinical research
- Can be a lobby, because they are still in active life (even if they have ceased working)
- Are not afraid of new examinations, or technologies
- Move, are not reluctant to travelling (e.g. to go to an expert centre)
- Are not resigned, are not accepting the disease
- Are less at risk of attrition in longitudinal studies (do not give up)

and so far are excluded from clinical and pharmaceutical studies because of their young age!

- Autosomal dominant forms of AD are a great model to develop disease-modifying drugs (cf. DIAN, GENFI), but:
  - Is the physiopathology the same whatever the mutations and similar to sporadic multifactorial cases?
  - Ethical issues
- Monogenic mutations account for 10% of EOAD (< 2% of LOAD) and 20-40% of FTD
- Important to understand why sporadic cases have a large range of onset. It would lead to strategies to delay the disease(s).
- Important not to miss atypical phenotypes
- Need for research in Human and Social Sciences

Difficult diagnosis ?

- Biological and imaging studies give confidence in the diagnosis of AD, even when clinical features and age at onset (before 60) are not typical
- Young patients (and families) often in favour of autopsy to confirm diagnosis and to help research → helpful to validate biomarkers.
- Neuropathology does not differ in EOAD and LOAD
  - vascular burden higher in LOAD and genetic burden higher in EOAD

Role of young patients

- The (relatively rare) young patients of today are representative of what will be the much more numerous 'old' patients of tomorrow in terms of habits, likes and dislikes, abilities and skills (e.g. transportation mastering, information technology, communication, electronic devices…).
- In studying this population we could anticipate the future needs the society will have to face.
- International collaborations mandatory!

From labels to legacy: deepening our understanding and caring for dementia

Peter J. Whitehouse MD-PhD
Professor, Case Western Reserve University and University of Toronto
President, Intergenerational Schools International

SCHOOL OF MEDICINE CASE WESTERN RESERVE UNIVERSITY

Baycrest

THE Intergenerational SCHOOL A COMMUNITY OF LIFELONG LEARNERS

Thanks to the Alzheimer Society of Canada

Labels –"timely" diagnosis of what and for what purpose?

- Dementia
- Alzheimer's
- Mild Cognitive Impairment
  - Pre
  - Early
  - Late
- Preclinical or symptomatic Alzheimer's
- Subjective Cognitive Impairment
- **Aging Associated Cognitive Challenges**

Dementia is a changing label

Japan and Asia from Chiho to Ninchisho

American psychiatry Major Neurocognitive Disorder

Article

dementia

Dementia
10(4) 475–486

DOI: 10.1177/1471301211416616
dem.sagepub.com
SAGE

Government, professional and public efforts in Japan to change the designation of dementia (*chihō*)

Misa Miyamoto
National College of Nursing, Japan

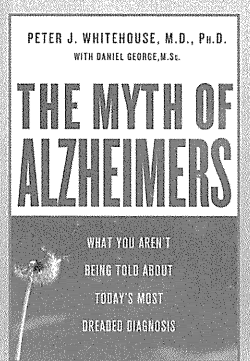
Daniel R. George
Penn State College of Medicine, USA

Peter J. Whitehouse
Case Western Reserve University, USA

Alzheimer's is an outmoded concept, maybe even a cognitively challenged one

G7 process is ending ("curing") Alzheimer's disease as a label by rightfully focusing on broader concept of dementia

What is the Myth of Alzheimer's?



- Alzheimer's is heterogeneous i.e. not a single disease
- Alzheimer's is related to severe brain aging – perhaps the same processes

Implications

- Cure or cures will be perhaps impossible, especially practically
- Care, community, prevention and public health will be key

www.themythofalzheimers.com

Alzheimer's Language Games
Is it "just" aging?

Reflection and Reaction

Organising the language of Alzheimer's disease in light of biomarkers

Criteria for Alzheimer's disease dementia have served clinicians remarkably well for the past 25 years despite the fact that they predate knowledge of biomarkers, quantitative neuroimaging, other dementias of late life, and the amyloid hypothesis.[1] Both probable and possible diagnoses of Alzheimer's disease define advanced disease and are highly accurate in that they are strongly correlated to neuropathological changes seen at post mortem.

for typical Alzheimer's disease, which is further characterised as dementia or prodromal Alzheimer's disease. The definition of prodromal Alzheimer's disease is nearly identical to the criteria used in clinical trials and the Alzheimer's Disease Neuroimaging Initiative for "mild cognitive impairment due to Alzheimer's disease" except for the biomarker requirement. If the memory impairment is absent, then the diagnosis could be atypical Alzheimer's disease dementia, mild

Published Online
October 11, 2010
DOI:10.1016/S1474-4422(10)70249-5
See Online/Position Paper
DOI:10.1016/S1474-4422(10)70223-4

Asymptomatic Alzheimer's disease – Reisa Sperling (but "its aging")

Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup

Reisa A. Sperling[a,*], Paul S. Aisen[b], Laurel A. Beckett[c], David A. Bennett[d], Suzanne Craft[e], Anne M. Fagan[f], Takeshi Iwatsubo[g], Clifford R. Jack[h], Jeffrey Kaye[i], Thomas J. Montine[j], Denise C. Park[k], Eric M. Reiman[l], Christopher C. Rowe[m], Eric Siemers[n], Yaakov Stern[o], Kristine Yaffe[p], Maria C. Carrillo[q], Bill Thies[q], Marcelle Morrison-Bogorad[r], Molly V. Wagster[r], Creighton H. Phelps[r]

Neuropathology – not definite but "disengaged" –Brad Hyman but "it's aging"

National Institute on Aging–Alzheimer's Association guidelines for the neuropathologic assessment of Alzheimer's disease

Co-chairs: Montine and Hyman

Members: Beach, Bigio, Cairns, Dickson, Duyckaerts, Frosch, Masliah, Mirra, Nelson, Phelps, Schneider, Trojanowski, and Vinters

DRAFT

Biomarkers are unproven in many ways but being promoted

Medscape EDUCATION

Amyloid Imaging 101: Why, What, When, and for Whom

Keith A. Johnson, MD
Co-Leader, Neuroimaging Program
Massachusetts Alzheimer's Disease Research Center
Professor of Radiology
Harvard Medical School
Boston, Massachusetts

Lilly Backs Lawsuit Against CMS Over its Alzheimer's Diagnostic Drug

ARTICLE | COMMENTS (4)

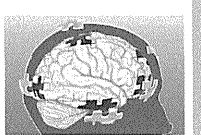
ALZHEIMER'S AMYVID CMS DEMENTIA ELI LILLY

Email Print

By ED SILVERMAN

Nearly a year ago, the Centers for Medicare & Medicaid Services denied coverage for an Eli Lilly (LLY +0.43%) imaging agent to be used in diagnosing Alzheimer's. In reaching its decision, CMS cited a lack of evidence that the agent, called Amyvid, could improve health outcomes. As a result, CMS greatly narrowed the potential use of the agent, dealing Lilly a significant setback.

Now, Lilly is fighting back.



— Getty Images/Universal Images Group

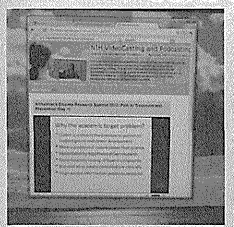
Basic science is Alzheimer's/dementia is in trouble –scientifically and morally

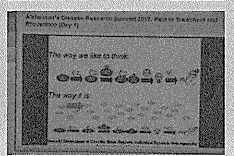
Mice get Mouseheimer's disease, not Alzheimer's disease

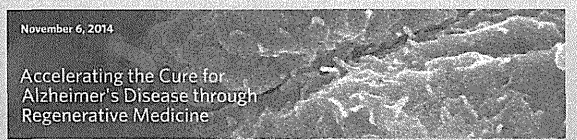
Problems of replicability

Problems of fame and fortune

Alzheimer's Disease Research Summits
NIH May 2012 and Duke November 6, 2014
Cure or even effective treatment by 2020?







Nov. 6 conference at Duke will allow both national experts and concerned laypeople to catch up on the use of stem cells in Alzheimer's research, a direction that is showing promise.

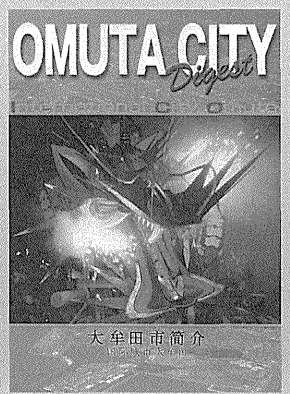
Care is not something we only do while waiting for a cure

Only politicians and those trying to raise money talk about cure as realistic in any time span but especially short…

And what would "cure" look like, back to "normal"?

Age and dementia-friendly communities movements

Japan -Omuta City



Germany - Arnsberg

Person (with dementia and otherwise) -friendly communities are what we need

Schools are essential to community and human flourishing

Intergenerational relationship and story-based learning is the most powerful

Literacy and especially ecoliteracy is essential to human survival

The Intergenerational School

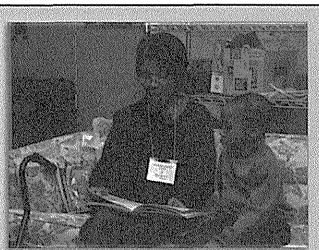
Grew from 30 to 240 K-8 Students
95% African American
65% Poverty rate

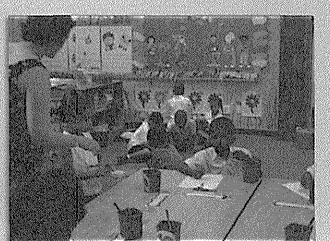
Last year served 330+ adult learners

Consistently one of the top performing charter schools in Ohio

Internationally and nationally recognized for intergenerational programs and student success

www.tisonline.org





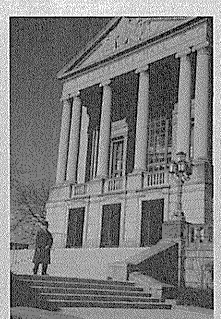
Intervention

Qualitative results

Quality of life:

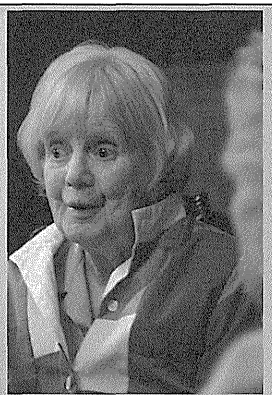
Main themes	Sub themes
Perceived health benefits	Reduced stress and depression Youthful energy Cognitive stimulation
Sense of purpose and sense of usefulness	Role continuation Reminiscence Joy of teaching children
Relationships	Physical touch Proxy grandchildren Racial reconciliation Acceptance Reciprocity

"Concert offers different take on Alzheimer's disease" Cleveland Plain Dealer
Enhancing the role of art, music, and dance

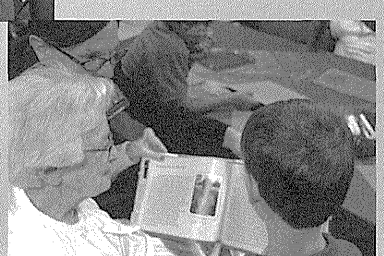


Legacy Projects

Freeway Fighters
1960's environmental activists



The Legacy of Clark Freeway Fighters



OLD LIVES TALES

"Occupy Nature": Passing Activism Across Generations

In the early 1960s, a group of community activists in Cleveland calling themselves the "Freeway Fighters" began mobilizing. The target of their protest was a proposed superhighway that would tear through 200 acres of undeveloped marsh, deciduous nature center, and sully a stream called Doan Brook that meandered through several eastside neighborhoods and into the city's cultural gardens in Rockefeller Park before emptying into Lake Erie. Championing the superhighway was a powerful and politically connected county engineer who considered the nature center and its waterways "a dinky little park" with a "two-bit duck pond" and argued the parkland was better viewed from a car than on foot.[1] It was the height of the post-Eisenhower freeway boom, and the building frenzy seemed an unstoppable cultural force.

But it was also the era of civil rights and antiwar movements, and protest was in the air. Galvanized by the threat to their neighborhoods, the Freeway Fighters held public forums to educate the community, organized letter-writing groups, and arranged walks through the parklands with local politicians. "Better ducks than trucks" was their unifying cry. In 1970, after the group had waged a 7-year struggle, Ohio governor James Rhodes officially scrapped the superhighway plan. Since then, more than 250,000 children have taken classes at the nature center on Doan Brook, whose oxygen-rich waters now flow into Lake Erie.

Many of the Freeway Fighters have since died, and those still living are experiencing the challenges of old age. Even so, the legacy of their activism is still embodied in the trees, waterways, and wildlife surrounding the nature center. One major beneficiary of the Freeway Fighters' efforts has been The Intergenerational School (TIS), a Cleveland charter school located on a bluff above Doan Brook that uses the landscape as an educational resource and venue for intergenerational programming.

In March 2011, TIS students aged 12 to 14 visited a local retirement community called Judson Park—also located near Doan Brook—where nine Freeway Fighters resided. Students were charged not only with recording the stories of these activists, but also with expressing gratitude for the legacy they had left the region.

When students arrived at Judson Park, they shook hands with their elder partners and split into small groups for interviews. One Freeway Fighter, Kay Fuller, a 94-year-old woman whose memory is now challenged by mild to moderate dementia (Figure 1), energetically described to her young partners how the fight against the superhighway

Figure 1. With a picture of the nature reserve in front of her, Kay Fuller describes her role as an activist to students from The Intergenerational School.

thrust her into the unexpected position of a movement leader: "I just couldn't believe that they would put a freeway through there ... but I never fought anything in my life. I had always been shy and afraid of my own voice, so I really had to work on it." Then a housewife and mother of three young children, Mrs. Fuller eventually found her voice as testifying at the local city council as well as before the U.S. Congress. When students asked what practical advice Mrs. Fuller would give their generation, she paused to reflect before saying: "I think you should take the lesson that, if there is something that is worthwhile, you should be aware of it and fight for it."

In their reflective writing after the encounter, students expressed admiration at how the Freeway Fighters had protected the local neighborhood, often assimilating the fraternal language of their elder partners. As one student wrote: "There are some things that you really need to stand up and fight for when you think they're wrong. You can't just sit there and let people run over you, because that highway would've destroyed a beautiful part of this city that now is very integrated." Another student concurred: "The freeway would've destroyed [our neighborhood]. It would have become neglected and empty." Student narratives were combined with their interview

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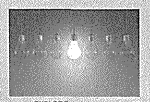
Legacy Center Toronto

1 World, 1 Book

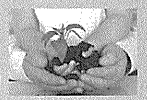
ENGAGE
dreams / aspirations

7-Gen Resources



EXPLORE
needs / interests

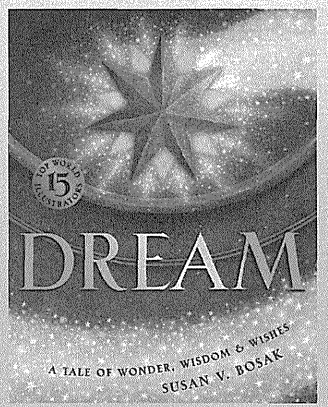
Legacy Projects



ENABLE ACTION
assets / strengths

YOU 177 is a r/evolution in the way we think and solve problems that strategically empowers and connects youth, adults, and elders of all ages and abilities for inspired lives, stronger communities, and a sustainable world. 1 World, 7 Generations, 7 Billion People and YOU.

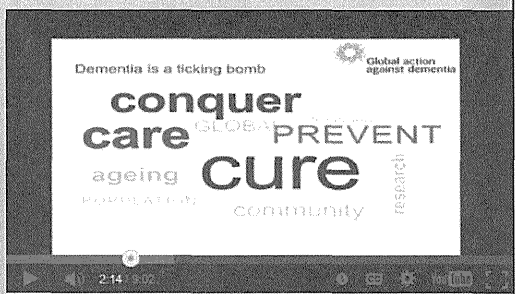
www.legacyproject.org



World Dementia Council lead by World Dementia Envoy –what will the **legacy** of the G7 be?

World Dementia Envoy address to ADI Conference

Dennis Gillings, World Dementia Envoy sends a message to the Alzheimer's Disease International Conference, San Juan, Puerto Rico, 2014



“Think like a mountain” – a powerful metaphor to rethink dementia

- What is **aging** (in community) about?
- How can **science** contribute to **life**?
- How central is the **brain** to thinking and valuing?
- What does it mean to be a mortal **human being**?