Time bombs and tsunamis

The impact of negative language and images on people with dementia
Dementia is 'next global health time bomb' – an article from The Telegraph.

Obesity ‘is dementia timebomb’ – an article from The Express.

The dementia timebomb – an article from BBC Science.

G8 ministers warned to prepare for global dementia ‘time bomb’ – an article from The Times.
We are woefully unprepared for the great tsunami of dementia

By Cristina Odone  Health and lifestyle  Last updated: July 3rd, 2012

126 Comments  Comment on this article

How to Cope With the "Living Death" of Alzheimer's: Anticipatory Grief

For many caretakers, daily care isn't the worst part of dealing with Alzheimer's or other dementias. Grief is.

By Paula Spencer Scott, Caring.com senior editor

58 Comments  97% helpful

What is anticipatory grief?

Anticipatory grief is the emotional response people have to the loss of a loved one, felt in advance of the person's death. It's a common phenomenon among those who care for the terminally ill.

Overwhelming burden, cost of Alzheimer's to triple, report says

By Jacquie Visser, CNN

September 19, 2013 ... Updated 21:06 GMT (05:06 HKT)

Discuss. with other viewers and CNN

Alzheimer's: A living death both for the patient and their loved ones

By Dr. Robert LeFever

Published: 11:10, 27 March 2012 | Updated: 15:17, 27 March 2012

My friend Ivan does not recognise his wife. That is a tragedy for both of them. Alzheimer's disease has destroyed their life together. It only something could have been done earlier. This is now the hope of the Prime Minister for new suffers.

Ivan and I went through school, the army and medical school together. He was supremely fit and joined the SAS, eventually being their doctor. He could not have kept himself in better shape, physically and mentally.
Negative language can undermine positive images … and vice versa
Words that disempower

Onslaught
Silent Crisis
Ticking time bomb
Looming epidemic
Enemy of humanity
Tsunami
Burden
Plague

The ‘problem’

The ‘experience’

Hopeless
Living death
Degenerative
Inexorable
Battle
Agony

The ‘person’

Senile
Victim
Demented
Fading away
Them/They
Sufferer

Words that disempower
What is the **impact**?

- **Sensationalises** the disease; links it with idea of destruction and devastation
- Brings **fear** of old age to all of us
- Causes **denial** - reluctance to seek help
- Delays **diagnosis** – poorer outcomes
- Promotes social exclusion and **isolation**
- Leads to **hopelessness**, frustration and poor self-esteem
- **Dehumanises** the person – can lead to poor care
- **Lack of support** for carer and family
- Barrier to further **research**
- **Ignores** the testimonies of people with dementia
“People get to hear the word dementia and it is all lumped together and they think you are finished.
You are not finished at all…”

Pat, Scotland
“When first having a diagnosis, my thoughts were to think of a person in the end stages of dementia, not knowing that there is an in-between stage”

Member of Bradford focus group
(Nov 2013)
“We, the people in this action group, don’t want to be seen as **suffering** from dementia, this is a term we really do not like. We are getting on with it, **living with it** with laughter and love and that makes a difference. We are being **heard** and our **opinions valued**.”

Agnes Houston
‘Curl up and die’ words – from the new DEEP Guidelines

Words that should **never be used** to describe dementia or people with dementia.

These are words that…

- make people physically flinch when they hear or read them
- send out the message that a life with dementia is not worth living, that people are helpless and have nothing to contribute
- are negatively attached to the person rather than the condition of dementia
- create stereotypes

**Senile**
**Demented**
**Sufferer**
**Burden**
**Victim**
**Plague**
**Epidemic**
**Enemy of humanity**
**Living death**

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10 Things we can all do.....

• Think
• Use
• Supply
• Challenge
• Get the message across
• Give accurate information
• Raise awareness
• Involve
• Listen
• Support
Words that empower

Challenge
New ways of thinking
Opportunity
Investing

The ‘challenge’

The ‘experience’

Inclusion
Progressive
Contributing
Life after dementia
Major transition
Empowered
Adjustment

The ‘person’

Person with dementia
Living with dementia
Person with a diagnosis
Us/we/all of us
Valued

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Empowering images?
“As well as empowering ourselves by finding answers and roads out of despair, we should also empower the professional workers and explain to them that there is life after dementia.”

James McKillop
“I do not get it. We did nothing wrong to get this disease, and we need to speak up to let our voice be heard. We did nothing and no one should be ashamed of having it. I feel so much better when I share it with others than when I try to hide it”

Michael Ellenbogen
Next steps

• Adopt the new DEEP guideline “Dementia Words Matter”: dementiavoices.org.uk/resources/deep-guides
• Watch out for the new Call to Action through the DAA
• BBC coverage
• Comic Relief: Red Nose Day
• What else? Your ideas welcome…

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has”. Margaret Mead
References and links

• “Defusing the Dementia ‘time bomb’”: Toby Williamson, MHF (2012)
• “Perspectives on ageing with dementia”: Weaks et al, JRF (2012)
• Guidelines on "The ethical issues linked to the perceptions and portrayal of dementia and people with dementia" Alzheimer Europe (2013)

Programme web page:
http://www.jrf.org.uk/work/workarea/dementia-without-walls

Key resources and reports: http://www.jrf.org.uk/work/workarea/dementia-resources

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