Suicidal behaviour and cognitive disorders in late life – an overview

BRIAN DRAPER MD
Academic Department for Old Age Psychiatry
Prince of Wales Hospital, Randwick
ROBIN WILLIAMS
1951-2014

A radical activist to the very end

PETER MCGREGOR
1947-2008

PETER MCGREGOR, activist, academic, and writer, was one of Australia’s most committed and energetic souls. He was involved in many of the most significant campaigns of the past 40 years against apartheid and the Vietnam War, as well as campaigns on nuclear arms, asylum seekers, and David Hicks, about climate change and consumption.

The campaigns were often unpopular when McGregor took them up. Yet history has come down on his side more often than not. Perhaps his biggest coup was the conscription of a tree to Australia by a South African cricket team. McGregor and Menzies BMP were co-signers of the Anti-Apartheid Movement. With detail of the concept, wrote to Sir Donald Bradman, suggesting that Australians must play a more direct role in the war effort. Bradman, a keen cricket fan, agreed with the concept and responded positively.

McGregor’s influence was significant, and his work was recognized both within and outside the sporting community. He was a true radical, always willing to stand up for what he believed in. His passing is a loss to the Australian sporting world, and his legacy will continue to inspire future generations.
Presentation Outline

1. Cognition and Suicidal Behaviour
2. Self-Harm in Late Life and Subsequent Risk of Dementia
3. Thoughts of Death & Suicidal Ideation in Dementia
4. Self-Harm in Dementia
5. Suicide in Dementia
6. Assisted Suicide and Rational Suicide in Dementia
Cognition and Suicidal Behaviour

Cognitive factors such as cognitive rigidity, poor problem solving, and reduced working memory (Giner et al, 2016) and impaired cognitive inhibition (Jollant et al, 2011) are associated with self harm, especially in middle age-old age.

There is also evidence that persons with borderline intellectual functioning have increased rates of suicidal behaviour (Hassiotis et al, 2011)
Cognitive Factors and Suicidal Behaviour in Depressed Older People

Major Depression
A series of case-control studies of older depressed people with & without a history of suicide attempts (SA)
Poor performance on tests of executive function, attention, and memory associated with SA in older people with major depression
Older depressed SAs had a perception of life problems as threatening and unsolvable, an impulsive approach to problem solving, and a tendency to ignore past experiences and neglect outcome probability when making decisions that are overly present-focused

(Dombrovski et al, 2008, 2010; Gibbs et al, 2009; Clark et al, 2011)
Cognitive Factors and Suicidal Behaviour in Depressed Older People

Major Depression

A second research group also used case control methods

Older depressed SAs had worse cognitive inhibition performance, especially on the motor component, than their non-suicidal depressed counterparts and this inability to inhibit intrusive information may predispose to suicide attempts.

Also an inability to inhibit neutral information access to working memory and delete irrelevant information which may impair the capacity to respond adequately to stressful situations.

Is Self-Harm in Late Life Associated with an Increased Risk of Developing Dementia?

- Self-harm in late life might be a manifestation of prodromal dementia, suicide neuropath studies have conflicting results regarding rate of AD changes.
- In some the course of dementia includes a first episode of depression before cognitive decline is apparent.
- Older persons with major depression who were apolipoprotein Eε4 carriers had an increased suicide attempt history and worse cognition than those who were not carriers (Hwang et al, 2006).
Is Self-Harm in Late Life Associated with an Increased Risk of Developing Dementia?

- Taiwan National Health Insurance Database study
- Significantly increased risk of subsequent dementia found in a nationwide study involving a large cohort of non-demented suicide attempters aged 65+ compared with age and sex-matched control subjects
- When those diagnosed with dementia within 1 or 3 years of the attempt were excluded, findings persist.
- Results were also independent of depression and other physical comorbidities (Tu et al, 2016)
Thoughts of death in older people

• Thoughts of death might be an adaptive process to acute or chronic life stress that is out of the person’s control

• There is a high risk of clinical depression when older people contemplate death, but most are NOT clinically depressed

• One Israeli community study of over 1700 individuals aged 50+ reported that thoughts of death were associated with impaired time orientation (Ayalon & Litwin, 2009)
How Common is Suicidal Ideation in Older People?

Almeida, Draper et al (2012) - over 20 thousand patients aged 60+ attending GP in Australia

- 4.8% suicidal thoughts last 2 weeks on Suicide Subscale of DSI
- Poor social support, history of depression, concurrent anxiety & depression, prevalent anxiety, pain, no religious practice were significant factors

Fassberg et al (2013) - 269 97-year olds without dementia in Sweden

- Over past month, 11.5% had suicidal feelings, 0.8% serious.
- Most (77.4%) did NOT fulfil depression criteria

Shen et al (2018) - 336 Aboriginal Australians aged 60+

- On PHQ-9, 10.4% suicidal thoughts last 2 weeks, strongly associated with current depression on PHQ-9
Suicidal Ideation in Dementia

**SELF REPORT**
Rubin & Kinscherf (1989) 2%
Draper et al (1998) 1%

**CAREGIVER REPORT**
Rubin & Kinscherf (1989) 15%
Teri et al (1992) 9% “at least weekly”
Suicidal Ideation, the Wish to Die, and Dementia
Draper et al (1998)

221 memory clinic patients
On self report - 5% “life not worth living”
- 3% “wish to die”
- 1% “suicidal ideation”

All patients who “wished to die” or had suicidal ideation scored 12 or more on HRSD. Two thirds were clinical depressed, one third had major depression.

Suicidal ideation and the “wish to die” were significantly associated with presence of depressive symptoms but only in patients with AD (r = 0.49, p<0.0001)
Cognitive Impairment, Dementia and Self Harm in Older People

- Two systematic reviews of DSH in older people (1985 – 2004) found less than 10% of subjects had a primary diagnosis of dementia, most reported psychiatric comorbidity, impulsivity & mild – moderate cognitive decline (Draper, 1996; Chan et al., 2007). Prescription drug overdose was the most common method, especially benzodiazepines.

- More impulsive DSH may occur with frontal cognitive impairment (Pierce, 1987; Draper, 1994; Rosenberg and Rosse, 2003).

- Suicide attempters aged 70+ had worse cognitive function on MMSE than controls with similar depression scores on MADRS. At 1 year FU, cognition remained impaired despite improvement in mood (Olsson et al, 2016).
Self harm behaviours in Sydney nursing homes (Draper et al, 2002; 2003)

- 600 nursing home residents aged 65+
- 59% chart diagnosis dementia, 82% cognitively impaired on AMTS
- Rated morning & evening on the Harmful Behaviours Scale by NH staff
- In the previous week, 14% showed evidence of overt self-harm behaviour (such as cutting, burns, eating foreign objects, hitting walls, doors etc)
- Intent was difficult to determine; however 14% burns, 25% cuts & 46% hitting episodes were regarded as intentional
• Overall quality of research on DSH in older people with dementia is poor with most studies being retrospective, selective and underpowered (Draper, 2010).
• Few prospective or longitudinal studies that examine outcomes
• Recent population-based studies & qualitative studies
Population-based Studies

Two studies involving admissions to NSW hospitals in the 10 year period 2003-2012 with linked mortality data

- Intentional and unintentional poisoning in older people with & without dementia with 30 day mortality (Mitchell et al, 2015)
- Intentional self harm in older people with and without dementia & 12 month survival (Mitchell et al 2017)
Method

• Individuals aged 50+ years with and without dementia admitted to hospital for poisoning or self harm using linked hospital admission and mortality records during 2003-2012 in NSW.

• Diagnoses, external cause codes, intentionality, and substance type were classified using the International Classification of Diseases, 10\textsuperscript{th} Revision, Australian Modification (ICD-10-AM).

• Comorbidities rated by the Charlson Comorbidity Index

• Hospital LOS, 28-day readmission and 30-day & 12 month mortality were examined by dementia status.

• Logistic regression examined univariate & multivariate associations of poisoning intent and demographic, comorbid and injury event characteristics
Study 1. Intentional & Unintentional Poisoning

• To compare the characteristics of older people with and without dementia hospitalised due to intentional and unintentional poisoning, and

• To examine the clinical outcomes and comorbidities by poisoning intent for older people with and without dementia.
Results: hospitalisations, 2003-2012

- **Unintentional poisoning**
  - 6,240 people 50+ years hospitalised
  - **581 (9.3%)** had dementia identified
  - Hospitalisation rates 60+ years:
    - **31.6 per 100,000** (95%CI: 30.6-32.6) for people without dementia
    - **69.5 per 100,000** (95%CI: 60.4-78.6) for people with dementia

- **Intentional poisoning**
  - 10,451 people 50+ years hospitalised
  - **314 (3.0%)** had dementia identified
  - Hospitalisation rates 60+ years:
    - **32.5 per 100,000** (95%CI: 31.5-33.5) for people without dementia
    - **56.4 per 100,000** (95%CI: 46.7-66.2) for people with dementia
Results: health outcomes

• Unintentional poisoning
  • 30-day mortality:
  • 5.7% dementia
  • 2.1% no dementia
  • 28-day readmission:
  • 13.8% dementia
  • 18.8% no dementia
  • Mean age-adjusted LOS:
    • 5.1 days for dementia
    • 4.2 days no dementia

• Intentional poisoning
  • 30-day mortality:
  • 1.6% dementia
  • 2.3% no dementia
  • 28-day readmission:
  • 21.0% dementia
  • 23.0% no dementia
  • Mean age-adjusted LOS:
    • 12.7 days dementia
    • 8.6 days no dementia
Results: associations of poisoning intent

- Unintentional poisoning more likely to involve:
  - males than females (OR: 1.21; 95%CI: 1.13-1.28)
  - older age groups than people aged 50-59 years
  - people with dementia (OR: 3.31; 95%CI: 2.88-3.82)
  - people with multiple comorbidities than no comorbidities
  - people residing in aged care facilities than home (OR: 5.44; 95%CI: 4.43-6.67)
  - people residing in health service facilities than home (OR: 4.56; 95%CI: 4.06-5.13)
Study 2: Intentional Self-Harm

There were 12,111 individuals aged 50 years and older who were admitted to hospital as a result of intentional self-harm in NSW from 2003-2012.

Of these, 427 (3.5%) hospitalisations were of individuals who had dementia.
Characteristics of intentional self-harm for individuals with and without dementia aged 50 years and older in linked hospitalisation-mortality data in NSW, 2003-2012

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Dementia (n=427)</th>
<th>No dementia (n=11,684)</th>
<th>$\chi^2$ (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>228</td>
<td>5,051</td>
<td>17.3 (1)*</td>
</tr>
<tr>
<td>Female</td>
<td>199</td>
<td>6,633</td>
<td></td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>79</td>
<td>7,000</td>
<td>663.5 (3)*</td>
</tr>
<tr>
<td>60-69</td>
<td>67</td>
<td>2,654</td>
<td></td>
</tr>
<tr>
<td>70-79</td>
<td>138</td>
<td>1,185</td>
<td></td>
</tr>
<tr>
<td>80+</td>
<td>143</td>
<td>845</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>248</td>
<td>6,169</td>
<td>0.06 (2)</td>
</tr>
<tr>
<td>Married/de facto</td>
<td>158</td>
<td>4,991</td>
<td></td>
</tr>
<tr>
<td>Not known</td>
<td>21</td>
<td>524</td>
<td></td>
</tr>
<tr>
<td><strong>Number of comorbidities</strong> (excluding dementia)**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>231</td>
<td>8,726</td>
<td>129.4 (2)*</td>
</tr>
<tr>
<td>One or two</td>
<td>149</td>
<td>2,597</td>
<td></td>
</tr>
<tr>
<td>Three or more</td>
<td>47</td>
<td>361</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.0001,**p<0.001, ***p<0.01, ****p=0.05.
Characteristics of intentional self-harm for individuals with and without dementia aged 50 years and older in linked hospitalisation-mortality data in NSW, 2003-2012

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Dementia (n=427)</th>
<th>No dementia (n=11,684)</th>
<th>( \chi^2 ) (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mental health diagnoses</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>149 (34.9)</td>
<td>4,157 (35.6)</td>
<td>0.8 (1)</td>
</tr>
<tr>
<td>Schizophrenia-related psychoses</td>
<td>45 (10.5)</td>
<td>973 (8.3)</td>
<td>2.6 (1)</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>46 (10.8)</td>
<td>789 (6.8)</td>
<td>10.4 (1)**</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>128 (30.0)</td>
<td>4,336 (37.1)</td>
<td>9.0 (1)**</td>
</tr>
<tr>
<td><strong>Delirium</strong></td>
<td>50 (11.7)</td>
<td>269 (2.3)</td>
<td>142.2 (1)***</td>
</tr>
<tr>
<td><strong>Alcohol misuse and dependence</strong></td>
<td>111 (26.0)</td>
<td>3,667 (31.4)</td>
<td>5.6 (1)******</td>
</tr>
<tr>
<td><strong>Injury sub-mechanism</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-poisoning involving pharmaceutical drugs</td>
<td>294 (68.9)</td>
<td>9,546 (81.7)</td>
<td>62.6 (4)***</td>
</tr>
<tr>
<td>Self-poisoning involving alcohol, solvents, gas, pesticide, chemicals and noxious substances</td>
<td>23 (5.4)</td>
<td>656 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Hanging, strangulation and suffocation</td>
<td>12 (2.8)</td>
<td>137 (1.2)</td>
<td></td>
</tr>
<tr>
<td>Sharp or blunt objects</td>
<td>77 (18.0)</td>
<td>1,061 (9.1)</td>
<td></td>
</tr>
<tr>
<td>Other(^3) and unspecified</td>
<td>21 (4.9)</td>
<td>284 (2.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Location of incident</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>276 (64.6)</td>
<td>8,032 (68.7)</td>
<td>217.4 (4)***</td>
</tr>
<tr>
<td>Aged care facilities</td>
<td>54 (12.7)</td>
<td>221 (1.9)</td>
<td></td>
</tr>
<tr>
<td>Health service facilities</td>
<td>16 (3.8)</td>
<td>501 (4.3)</td>
<td></td>
</tr>
<tr>
<td>Other specified place</td>
<td>14 (3.3)</td>
<td>476 (4.1)</td>
<td></td>
</tr>
<tr>
<td>Unspecified place</td>
<td>67 (15.7)</td>
<td>2,454 (21.0)</td>
<td></td>
</tr>
</tbody>
</table>

\*p<0.0001, **p<0.001, ***p<0.01, ****p=0.05.
Hospitalised incidence rates for intentional self-harm for individuals aged 60+ with and without dementia by year and age group, linked hospitalisation and mortality records in NSW, 2003-2012
Health outcomes for intentional self-harm for individuals with and without dementia aged 50 years and older in linked hospitalisation-mortality data in NSW, 2003-2012

<table>
<thead>
<tr>
<th></th>
<th>Dementia (n=427)</th>
<th>No dementia (n=11,684)</th>
<th>$\chi^2$ (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>30-day mortality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>10</td>
<td>352</td>
<td>0.6 (1)</td>
</tr>
<tr>
<td>%</td>
<td>2.3</td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td><strong>12-month mortality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unadjusted</td>
<td>154</td>
<td>1,728</td>
<td>135.5 (1)*</td>
</tr>
<tr>
<td>Age-adjusted</td>
<td>154</td>
<td>1,728</td>
<td>t=-19.0 (402.1)*</td>
</tr>
<tr>
<td>28-day readmission for any cause</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unadjusted</td>
<td>86</td>
<td>2,578</td>
<td>0.02 (1)</td>
</tr>
<tr>
<td>Age-adjusted</td>
<td>86</td>
<td>2,578</td>
<td>t=16.0 (375.4)*</td>
</tr>
<tr>
<td>Mean (sd)</td>
<td>19.7 (21.4)</td>
<td>8.8 (14.0)</td>
<td>T-test (df)</td>
</tr>
<tr>
<td>Median</td>
<td>12.0</td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>Adjusted hospital LOS (days)</td>
<td>13.4 (4.1)</td>
<td>8.8 (3.4)</td>
<td>-21.5 (429.6)*</td>
</tr>
<tr>
<td></td>
<td>15.0</td>
<td>6.8</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.0001.
Associations of Mortality at 12 months for self-harm-related versus non-self-harm-related hospitalisations, linked hospitalisation and mortality records in NSW, 2003-2011

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mortality within 12 months</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dementia (n=154 self-harm and n=1,728 non-self-harm injury hospitalisations)</td>
<td>No dementia (n=34,046 self-harm and n=93,224 non-self-harm injury hospitalisations)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>OR</td>
<td>95%CI</td>
<td>OR</td>
</tr>
<tr>
<td>Mental health diagnoses¹</td>
<td>14.9*</td>
<td>10.6-21.0</td>
<td>22.5*</td>
</tr>
<tr>
<td>Depression</td>
<td>16.3*</td>
<td>11.1-23.9</td>
<td>16.7*</td>
</tr>
<tr>
<td>Schizophrenia-related psychoses</td>
<td>1.4</td>
<td>0.7-3.2</td>
<td>4.8*</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>10.7*</td>
<td>5.7-20.3</td>
<td>4.8*</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>10.3*</td>
<td>7.1-14.7</td>
<td>10.0*</td>
</tr>
<tr>
<td>Alcohol misuse and dependence</td>
<td>2.3*</td>
<td>1.4-3.7</td>
<td>1.9*</td>
</tr>
</tbody>
</table>

Age, sex and age-sex interaction-adjusted

*p<0.0001,**p<0.001, *** p=0.05.
Why do the very old self harm?
(Wand et al, 2018)

Qualitative study of 30 people aged 80+ interviewed within a month of self harm

Cohort study, 14 (47%) had dementia, 13 (43%) had MCI

Themes which emerged for the reasons for self-harm included ‘enough is enough’; ‘loneliness’; ‘disintegration of self’; ‘being a burden’; ‘cumulative adversity’; ‘hopelessness and endless suffering’; ‘helplessness with rejection’; and ‘the untenable situation’ – this latter theme was prominent in those with dementia

Issues included: Loss of and regaining control; Alienation, disconnection and invisibility; Meaninglessness and a raison d’etre; Accumulated suffering and a “painful life”
Suicide in Dementia

Historically, suicide regarded as uncommon in persons with dementia but data often excludes early dementia (Harris & Barraclough, 1997).

More recent reviews (e.g. Haw et al 2009; Draper, 2015) have also concluded that overall risk of suicide in dementia is low.

However, case reports & series of increased suicide risk in early dementia esp. with preserved insight, comorbid depression & frontal impairment.

**Snowdon & Baume (2002)** – 15/210 (7%) suicides had possible dementia of which 13 were depressed.

**Waern et al (2003)** – In a controlled psych autopsy study dementia had OR of 1.5 for risk of suicide.
Case Register Studies Suicide in Dementia


- Nationwide longitudinal study from Denmark using register linkage data; hospital-diagnosed dementia was associated with an elevated risk of suicide particularly in those aged 50-69 years where the relative risk was 8.5 in men, 10.8 in women.
- The risk was higher in the first 3 months after diagnosis particularly in men where 25% died in this period
- Controlling for mood disorders reduced but did not eliminate the increased risk
Case Register Studies Suicide in Dementia

Purandare et al (2009) – 9-year clinical survey of suicides in England & Wales, 118 cases with dementia matched with non-dementia suicides that had been in contact with MH services previous year.

Known suicide risk factors less common in dementia cases; yet, 69% had psychiatric comorbidity (85% in YOD), 44% had history of self harm (72% in YOD), 19% history of alcohol abuse (50% YOD), 10% psychosis

Self-poisoning, drowning & hanging most common methods

43% life events 3 months before suicide
39% felt to have been preventable
Case Register Studies Suicide in Dementia

Seyfried et al (2011)
US national cohort DVA study (2001-2005) of suicide in dementia aged 60+ compared with non-suicide dementia
241 cases – increase risk with white race, depression, history of psych hospitalisation, prescription antidepressants/anxiolytics.
75% had a new dementia diagnosis
Majority were firearm deaths
NH admission associated with lower risk

Murphy et al (2017) - nationwide study of suicides in Australian residential facilities using National Coronial Information System, around 18% had dementia
Does Diagnostic Disclosure of Dementia Increase Risk of Suicidal Behaviour?

People fear being diagnosed with dementia and many doctors fear the consequences of frank disclosure (Tarek et al, 2008)

Disclosure of dementia diagnosis did not prompt a catastrophic emotional reaction in most people, and rather provided some relief once an explanation for symptoms was known (Carpenter et al, 2008)

Aminzadeh et al (2007) - In first week after diagnosis, three broad categories of emotional responses:
− responses suggesting a lack of insight and/or an active denial of the diagnosis;
− grief reactions/emotional crisis related to the experience of actual or anticipated losses associated with dementia;
− positive coping responses to maximize the disease outcome.
Type of Dementia

Overall there is very limited data on dementia type

Erlangsen et al (2008) – Risk higher in AD compared to VaD
Seyfried et al (2011) – no association with specific diagnosis,

Some suggestion of increased in FTD, particularly semantic dementia (Sabodash et al 2013; Alberici et al 2012)

Huntington’s disease – 3x increased risk of suicide but unclear how many have cognitive impairment at dementia level of severity

HIV/AIDS – increased suicide risk but unclear how many are cognitively impaired
Management of suicide risk in the pre-symptomatic and early diagnosis of dementia
Draper et al (2010)

Recommended to adopt guidelines developed for Huntington’s disease

1. If a test for a gene or biomarker is proposed, pre-test counselling required to explain the risks & benefits of testing

2. A time lag between the initial visit & provision of results as 40% abandon testing & individuals need time to decide

3. Test results & diagnosis always provided face to face

4. Involvement of the family with the consent of the person with dementia is desirable to assist in planning and provide emotional support.
Management of suicide risk in the pre-symptomatic and early diagnosis of dementia

5. Tailor disclosure to suit the needs of the patient, using a stepped procedure to ascertain the person’s desire to know and exploring patient reactions to diagnosis to minimise catastrophic reactions

6. Message should be given in a simple easy to understand manner, emphasising that progression is slow, QOL can be maintained and symptomatic treatments are available

7. Realistic hope about the future should be provided.

8. An ongoing commitment to provide support & care to patient & family
Author argues for euthanasia tribunals

Maev Kennedy

LONDON: The author Sir Terry Pratchett is calling for euthanasia tribunals to give sufferers from incurable diseases the right to medical help to end their lives.

Pratchett insisted in a lecture broadcast on Monday that “the time is really coming” for legalising assisted death.

Pratchett, author of the bestselling Discworld fantasy novels, was diagnosed two years ago with a rare form of early onset Alzheimer’s disease – a discovery he memorably described, when he broke the news on the Discworld News website, as “an embuggerance”.

In his lecture, “Shaking Hands With Death”, the author volunteered to be a test case before a euthanasia tribunal himself.

The tribunal panels would include a legal expert in family matters and a doctor with experience of serious long-term illness.

“If granny walks up to the tribunal and bangs her walking stick on the table and says ‘Look, I’ve really had enough, I hate this bloody disease and I’d like to die, thank you very much young man’, I don’t see why anyone should stand in her way.”

He said there was no evidence from countries where assisted dying was allowed of granny being coerced into dying so relatives could get their hands on her money.

“Choice is very important in this matter. But there will be some probably older, probably wiser GPs, who will understand. The tribunal would be acting for the good of society as well as that of the applicant – and ensure they are of sound and informed mind, firm in their purpose, suffering from a life-threatening and incurable disease and not under the influence of a third party.

“If I knew that I could die, I would live. My life, my death, my choice.”

His lecture came a week after a British woman, Kay Gilderdale, was cleared of attempted murder for helping her 31-year-old daughter to commit suicide following years of suffering from the chronic fatigue syndrome ME.

However, days earlier Frances Inglis, who killed her 22-year-old son by heroin injection believing he was left in a “living hell” after severe brain damage in a road accident, was found guilty of murder and sentenced by majority verdict to a minimum of nine years in jail.

Pratchett, who made his comments at the annual BBC Dimbleby lecture, has previously criticised the existing law and the risk faced by any relatives who help a family member to die of being charged with murder.

Of his own Alzheimer’s, he said: “It is not nice and I do not wish to be there for the endgame.”

Two polls published in Britain on Monday found significant popular support for euthanasia.
Some Contemporary Views on Dementia & Rational Suicide

• Being ‘understandable’ is not equivalent to being ‘rational’
• “What appears to be irrational for some is considered quite rational in other cultural contexts” (Battin, 1984).
• Prado (1998) condoned ‘pre-emptive’ suicide - to avoid demeaning decline and needless suffering.
• It has been argued that persons with early dementia have a Kantian ‘moral duty’ to commit suicide before they become a burden on society (Cooley, 2007)

Baroness Warnock (84), a veteran UK government advisor and one of Britain’s leading moral philosophers stated in an interview with the Church of Scotland’s magazine - Life and Work that:

Elderly people suffering from dementia should consider ending their lives because they are a burden on the National Health System (NHS) and their families September 2008
Rational Suicide and Dementia

Davis (2013) argued that the move towards pre-symptomatic diagnosis of AD, makes rational suicide a more feasible option for those so inclined. She suggested that the reasons that a person might consider rational suicide included to conserve financial assets, to reduce family burden of care, and to allow people to end their lives “with a final chapter that is consonant with the narrative as a whole”.

Davis proposed that researchers & clinicians needed to acknowledge the option of pre-emptive suicide and provide information about biomarkers to research participants and patients so that they can make an exit strategy if desired.

Draper (2014) identified two specific concerns with Davis’ viewpoint. First, it ignores the inability of biomarkers to give accurate prediction of onset of symptomatic disease, quality of life or decision-making capacity (Draper, 2014). Second, it can be argued that from a moral viewpoint, suicide cannot be evaluated solely in terms of personal autonomy as communal values also play a role. Clinicians and researchers have broader ethical responsibilities as the impact of suicide upon families and health professionals can be profound.
Physician Assisted Suicide & Dementia

- The first person to die by suicide using Dr Kevorkian’s ‘suicide machine’ was a 54-year-old woman with early Alzheimer’s disease, who was said to have persuaded him that her decision was rational and the result of long and careful reflection.
- Few requests for PAS made by people actually suffering from dementia, 4 known cases had early YOD with atypical features (Hertogh et al, 2007)
Euthanasia, Physician-Assisted Suicide (PAS) and Dementia

In the Netherlands euthanasia is legally justified only if the physician is satisfied that the patient’s request is voluntary, well-considered, sustained well-informed and that he/she was fully competent at the time of the request and the physician is satisfied that the patient perceives his or her situation in terms of unbearable or hopeless suffering (Hertogh, 2005).

Few “experts in the field” consider that patients with dementia satisfy these criteria (Hertogh, 2005).

Arguments about the injustice of precluding patients with dementia from self-determination and access to PAS have been put forward (Post, 2007)
Advance Directives and Dementia

Advance directives are controversial and fraught with difficulties in the context of dementia. Advance directives rely on the concept of patient autonomy – the authority of the former competent self to govern the welfare of their later, non-competent selves (Davis, 2002)

Critics have highlighted
- the constraints of being able to imagine ourselves with different abilities, needs and preferences in radically different circumstances
- the difficulties in projecting decisions to future states or personal identities of ourselves which may have changed due to physical or mental changes (Gedge 2004).
- the pre-dementia person and the same person with dementia are literally two different people and that any advance directive made by the pre-dementia person is effectively directed to someone else (Degrazia, 1999)
The Lived Experience of Dementia

“Fear is always a bad counsellor” (Hertoghe et al, 2007)

The lived experience of dementia differs from the imagined experience of dementia

“No solid support to the widespread assumption that dementia is necessarily a dreadful state of suffering” (de Boer et al, 2007; Hertoghe et al, 2006).
Conclusion

Mild cognitive impairment, particularly in cognitive inhibition, is common in older people who self-harm.

Self-harm in late life can occur in prodromal dementia in the context of a mood disorder & suggests the need to monitor cognition in such patients.

Clinicians should be aware that there is an increased risk of suicidal behaviour in the 3 months after dementia diagnosis, particular with comorbid depression.

However, the overall risk of suicidal behaviour in people with dementia is low.

Assisted suicide and euthanasia for people with dementia pose significant ethical challenges.
Thank you....... 

Any questions? 

Brian Draper: 
b.draper@unsw.edu.au