

**The right to know and the
right not to know:
Truth telling and dementia**

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www.med.unsw.edu.au/adfoap

If it were your spouse?

- **Imagine a 64 y.o. person with progressive memory problems has just been to a memory clinic**
- **The likely diagnosis is Alzheimer's disease**
- **If it were your spouse, do you think s/he should be told?**
- **If your spouse was anxious, scared stiff of having AD, do you think s/he should be told?**

If it were your spouse?

- **What if your spouse was depressed and had said they would suicide if there was diagnosis of AD? Do you think s/he should be told?**
- **What if your spouse was severely demented, could not retain information for >30 seconds? Do you think s/he should be told?**

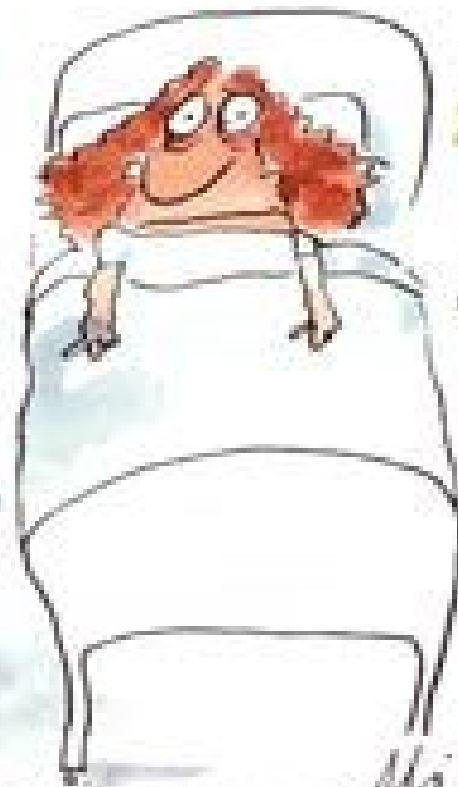
If it were you?

- If it were *you* at age 54, would you want to be told?
- If it were *you* at age 74, would you want to be told?
- If it were *you* at age 94, would you want to be told?

It is better to know?

- Anonymous person with AD
- “I felt something was seriously wrong...thought it might be AD which was the worst thing I could imagine”
- Dr: “Mental deterioration” → medication
- “When I picked up the script I knew it was AD
- “I felt let down not to be treated as capable of coping with the information
- “It is better to know what is happening and what to expect to be able to plan ahead”

See, Bernard? Julia's approach was just that tad more sensitive. OK- so who wants another crack at breaking the bad news?



Millard

The *shrunk walnut* award (or what pts/families tell me that their doctors have told them)



- “It’s Alzheimer’s/ dementia/ senility - nothing can be done”
- “What do you expect at her age?” (She was 73 yo)
- “He has dementia. He will get worse and then they will lock him up until he dies.” (*Doctor to wife of pt.*)

The debate

- ***Deontologists*** - competent patients have a moral right to know the diagnosis
- ***Consequentialists*** - a patient should be told the diagnosis only if knowing is more likely to benefit the patient ¹
- ***Autonomy vs Beneficence*** ²
- **Danger of hyper-cognitive society excluding the forgetful** ²

¹Erde E L et al J. Fam. Prac 1988; 26:401-6

²Post SG J Clinical Ethics 1998;9:71-80

Legal and ethical considerations



- Patients' moral and legal rights to receive the diagnosis¹
- Family do not have the right to withhold information which "belongs" to the pt.
- Question of confidentiality and informed consent to disclose to others

¹Smith AP, Beattie BL Can J Nerol Sci 2001;28: Suppl.1 S67-S71

The right *not* to know

- **In the past traditional paternalistic approaches justified withholding bad news to protect the patient¹**
- **Patients' may experience a sense of isolation and uncertainty following diagnosis²**
- **Diagnosis of mental illness increases patients' risk of being marginalised in care and service provision³**

¹Vandekieft G, American Family Physician 2001 64: 1975-8

²Mueller P, Postgraduate Medicine 2002 112(3):15-6, 18

³Arun J, Int J Geriatric Psychiatry 2001 16: 879-885

Effects of giving a diagnosis

- **Disclosure can facilitate development of a multidisciplinary treatment plan that includes the patient**
- **Pre-assessment expectations about diagnosis can influence the interpretation of diagnostic information**
- **Other causes of memory problems may be identified and treated**

Effects of giving a diagnosis ^{ctd}



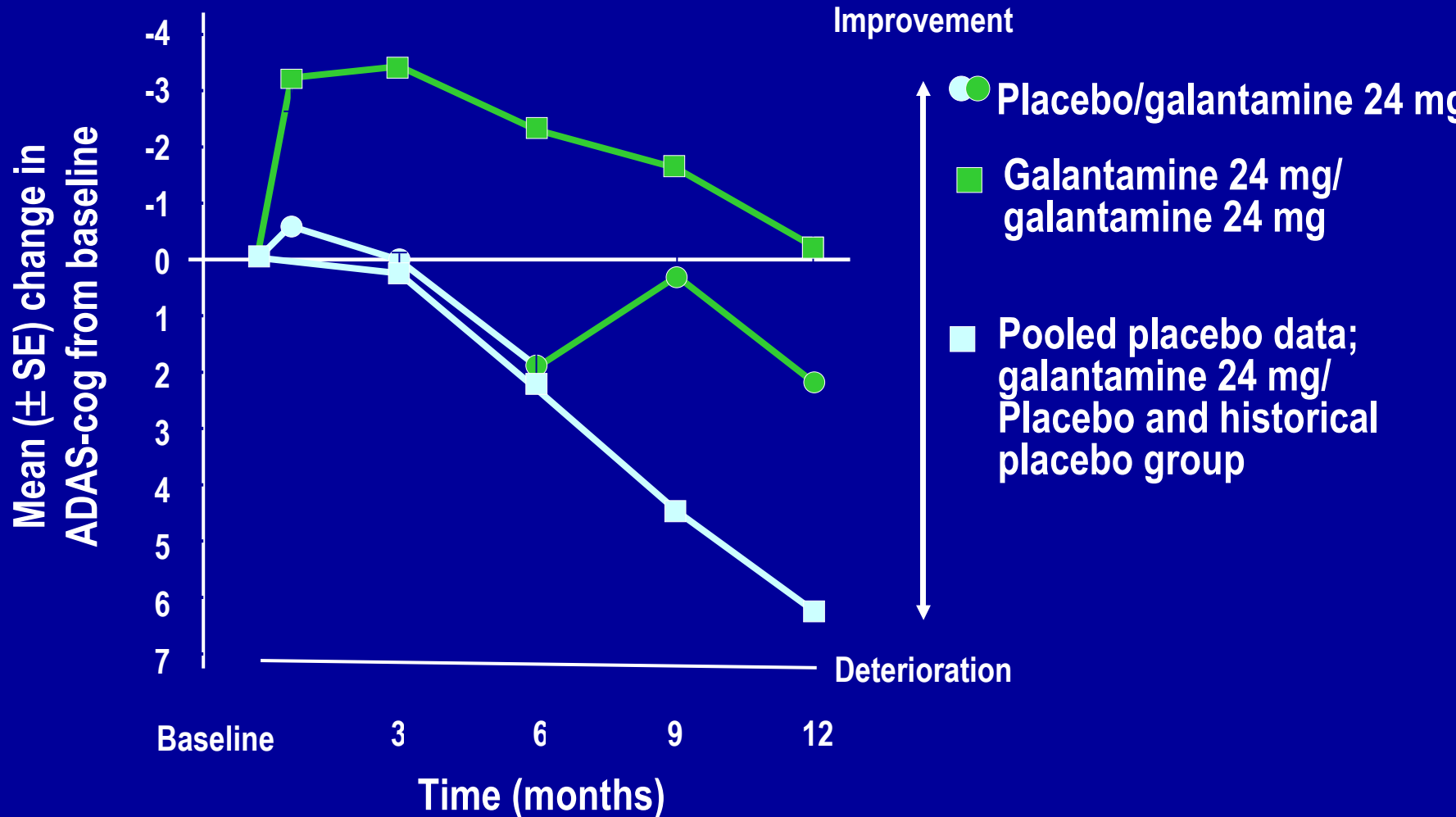
- Diagnosis of *possible* Alzheimer's Disease can be confusing
- Too much information can be overwhelming
- Disclosure of *no* dementia did not produce anticipated relief

Smith AP Beattie BL Can J Nerol Sci
2001;28:Suppl.1 S67-S71

Ten reasons to disclose a diagnosis of dementia

- Reversible cause possible
- A relief!
- Legal planning
- Financial planning
- Medical planning
- Life planning
- Work
- Driving
- Relations with the family
- Medication

Early treatment with galantamine may improve long-term outcome: GAL-USA-1/3



Reasons not to disclose a diagnosis of dementia

- **Assertion that earlier diagnosis is beneficial has not been tested**
- **Alarm to patient and family**
- **Insurance/work may penalise the patient**
- **Benefits of early medication implied but not proven**
- **Diagnosis may be incorrect**

Accuracy of diagnosis

- **Dementia in general - accuracy very high**
- **Comprehensive assessment ensures reasonably high accuracy in diagnosing AD in the very mildly impaired (89%)¹**
- **Uncertainty a concern when diagnosis is one of *possible AD*²**

¹Salmon D et al Neurology 2002; 59:1022-8

²Smith AP Beattie BL Can J Nerol Sci 2001;28:Suppl.1 S67-S71

What recipients of diagnosis say:

Patient

- **People in the community**
- **GP attendees**
- **Memory clinic patients**
- **Families**

Family

Clinician

Is Alzheimer's the new cancer?

- **Survey of 156 people living in a retirement village presented with two scenarios**
- **80% wanted to know if they had a diagnosis of AD, but**
- **92% wanted to know diagnosis of cancer**

Holroyd S et al JAGS, 1996; 44:400-3

Attitudes to “Truth Telling”

- 200 older people surveyed about being told a diagnosis of Alzheimer’s Disease versus cancer
- Most wanted to be told if they had Alzheimer’s Disease (92%) or terminal cancer(86.5%)

General patient survey

- Survey of 224 GP attendees in New Jersey
- 92% wanted to know their diagnosis of AD

Reasons:

- advance planning (94%);
- second opinion (62%);
- settle family matters, etc (36%);
- travel, vacation (16%)

Erde E L et al J. Fam. Prac 1988; 26:401-6

Dissatisfaction with information about diagnosis

- **Dementia carers surveyed to investigate the information provided by health professionals**
- **188 responses indicated**
 - **Most initial diagnoses were vague**
 - **Less than half of carers recalled being given information about management or prognosis of dementia**
 - **General practitioners are the professionals most commonly consulted**

An Irish Paradox

- **100 carers of 100 patients with diagnosed Alzheimer's disease**
- **83 carers said diagnosis should not be told to patient (“will cause depression”)**
- **71 carers said they would want to know their own diagnosis should they develop AD (“their right”)**

Attitudes to telling diagnosis of dementia: family survey in Virginia

- 57 families - 72% tell; 28% don't tell
- Reasons for telling: advance planning (64%); appropriate treatment (38%) and obtain a second opinion (31%)
- Reasons for not telling:
 - pt would be too upset (50%)
 - would not understand (67%)
 - no cure available (25%)

Family survey¹ ctd

- **53/57 (93%) of carers had been told Dx**
- **28/57 (49%) of patients had been told Dx**
- **Was it helpful for pt to be told Dx?:**
 - **1/3 helpful**
 - **1/3 not helpful**
 - **1/3 not sure**
- **American Medical Association² guidelines - to give diagnosis “if it all possible” - do not recognise complexity**

¹Holroyd S et al, 2002 IJGP; 17:218-221; ²Gultman R & Sleleski M (eds) 1999 Management and Treatment of Dementia, AMA

Nottingham Memory Clinic

- 50 patients with mild dementia (MMSE>18) and 50 carers
- 92% of pts wished to be informed of diagnosis
- 98% of carers wished to be informed if they were to develop AD
- 98% of patients and carers wished to be informed if they developed cancer
- 26% of carers did not want the AD Dx disclosed to the patient.

What providers of diagnosis think



- GPs
- Geriatricians
- Psychogeriatricians
- Psychology students

Who tells the truth? Who wants to know?

- 95% of GPs¹ tell cancer diagnosis always/often
- *but* only 39% tell diagnosis of dementia
- 93% of Queensland 1st year psychology students wanted to know diagnosis²
- Will there be a generation effect?
 - more receptive to diagnosis?
 - further from possible diagnosis themselves?
 - wanting more control, less passive and more knowledgeable

¹ Vassilas C, Donaldson J B J General Practice 1998; 48: 1081-2

² Sullivan K, O'Connor F Aging & Mental Health 2001; 5: 340-8

Nottingham survey (2000)

- 55 Drs sent survey → 40 responses from 25/38 geriatricians + 15/17 old age psychiatrists
- Having made a diagnosis of AD, how often do you tell the patient their diagnosis?

Always	0
Usually	40%
Sometimes	35%
Rarely	20%
Never	5%

Nottingham survey: Influencing factors

- Degree of insight of patient 88%
- Degree of certainty of diagnosis 68%
- Severity of dementia 75%
- Pt's express wish *not* to be told 75%
- Pt's express wish to be told 68%
- Certainty of type of dementia 45%
- Relative's wish pt not be told 38%
- Patient's personality 30%

Experience of diagnostic disclosure

- Study of 14 pts and their families who had assessment in memory clinic
 - ✂ → 3 probable AD cases:
 - Relief for 3 families - end of confusion
 - Disclosure facilitated pt care for all families

Experience of diagnostic disclosure

✂ → 5 possible AD cases

- Challenge for Dr to → Dx and uncertainty that could only be clarified over time
- Families held beliefs they came to clinic with
 - 3 families believed AD; 2 did not

✂ → 6 pts no AD (mean age 49 cf 85 yrs for AD)

- 4 of these pts had had depression
- Diagnosis was *not* a relief for 2 pts.

Patient and family experiences

- Although family members did not recall details of test results, they felt reassured by thoroughness of assessment process¹
- Relief experienced when the suspected cause of memory problems was identified¹
- Having a diagnosis facilitated discussion of patient's limitations with friends¹
- Diagnosis assisted in persuading the patient to accept assistance²

¹Smith AP Beattie BL Can J Neurol Sci 2001;28:Suppl.1 S67-S71

²Arun J, Int J Geriatric Psychiatry 2001 16: 879-885

To tell or not to tell

- Literature review 1966-1999¹ concluded that:
 - Most patients should be told
 - Most accept without catastrophic reaction
- The real challenge is when and how to inform
- How to communicate?
 - Truth will need to be told at some point
 - Then family support will be needed¹
 - Sensitively and to minimise despair²

¹Gordon M, Goldstein D Canadian Family Physician 2001;47:1803-9;

² Post SG J Clinical Ethics 1998;9:71-80

The art of truth telling in dementia



- Therapeutic privilege – withholding information justified if likely to injure the patient
- Depends on person's understanding
- Psychiatric symptoms influence decision

Should family always be told?

www.4allfree.com



Well, the good news is that we were able to save his leg.

Should family always be told?



- Most clinicians do, *but...*
- Should Drs ask patients for permission to tell family and/or other health professionals?
- Do patients retain equal status?

Fears expressed by families

Disclosing a diagnosis of dementia can lead to



- depression
- anxiety
- stigma
- “leprosy syndrome”
- giving up
- decompensating
- acknowledgement of family members’ own vulnerability
- risk of suicide

Family conflict and those who refuse to accept diagnosis

- *Fighter or fool?* Family member refuses to accept diagnosis
- *Families at war:* One side accepts and the other rejects diagnosis
- *Families and greed:*
 - where money is the issue
 - sibling rivalry; where will mum live?
 - where there's a will ... there's a dispute

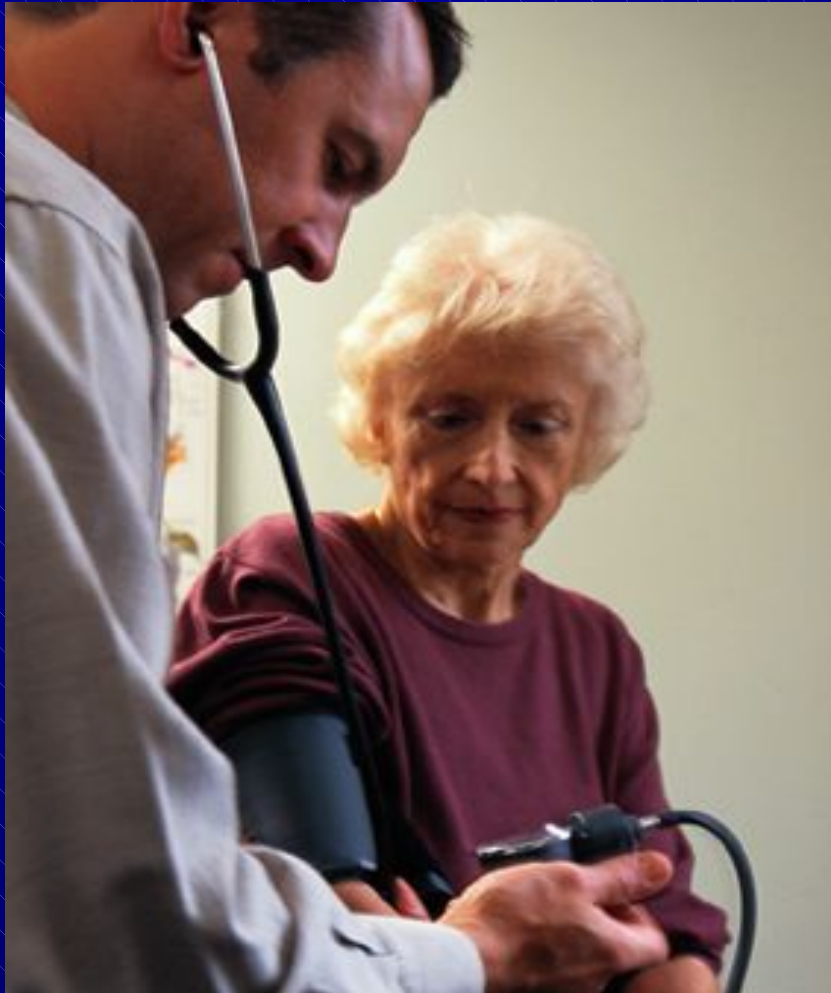
The cultural context

- Different views as to cause of dementia (evil spirits)
- Some non-Western cultures do not uphold the autonomy of individual and healthcare decisions are shared¹
- Family shame
- Tainted genes
- Different attitudes to protectiveness

¹Mueller P, Postgraduate Medicine
2002 112(3):15-6, 18



The clinician's dilemma



- The desire to communicate honestly and directly with the patient
- The family's reluctance to disclose the diagnosis
- The timing and approach to disclosure of the diagnosis

Gordon M, Goldstein D, Canadian Family Physician 2001;47:1803-9;

Doctors' negative attitudes

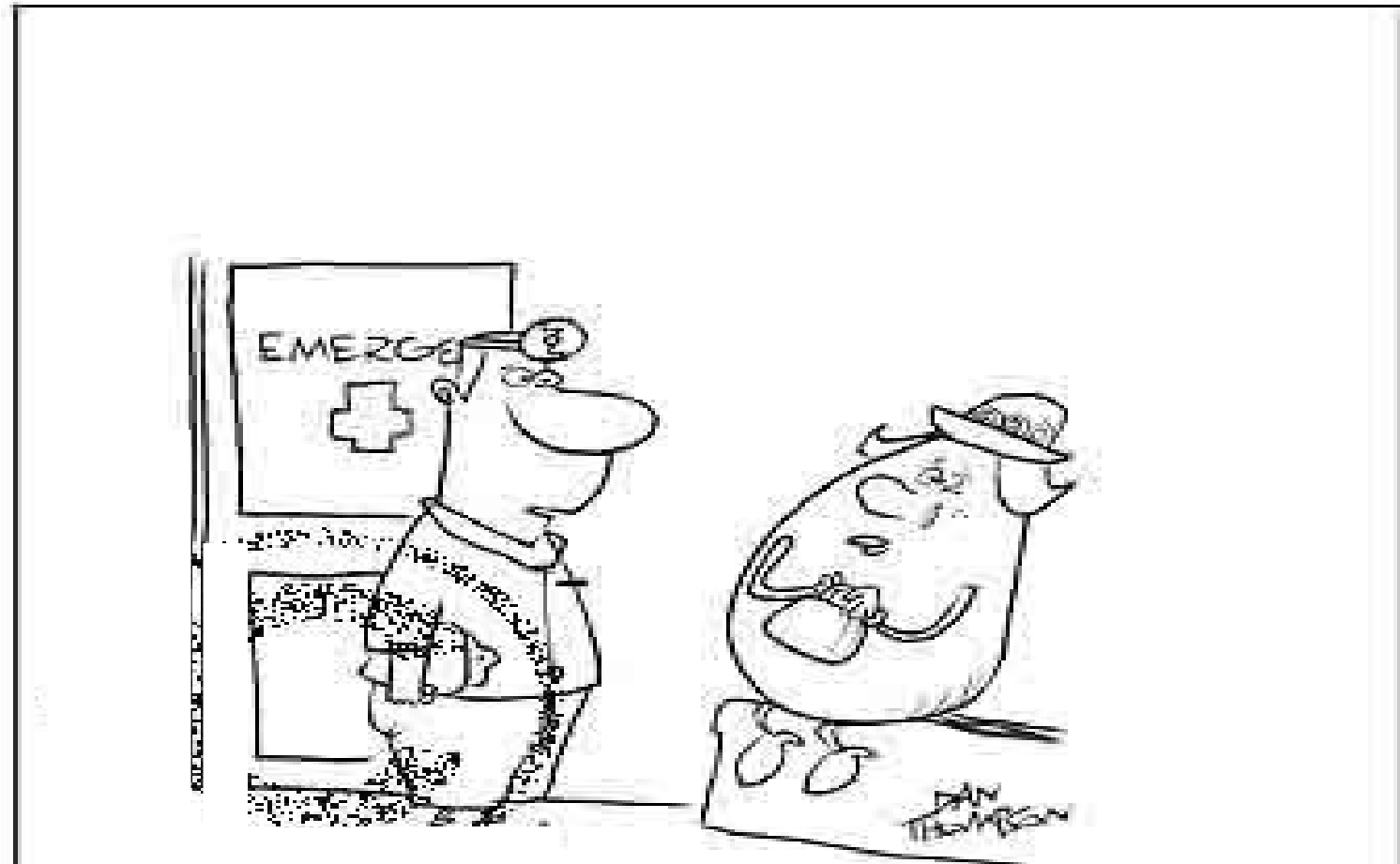
- Diagnosis seen to be of little benefit to the patient as no known cure available
- Uncomfortable with patients' responses and/or families' reactions to diagnosis¹
- Diagnosis may be a cause of unnecessary worry
- Sense of helplessness and hopelessness²

¹Vandekieft G, American Family Physician 2001; 64: 1975-8

²Keightley J, Mitchell A Aging & Mental Health 2004; 8: 13-20



Breaking bad news



**I'm afraid the news about your husband
is grim, Mrs Dumpty**

Breaking bad news

Recommended strategies¹

- prepare patient for possible diagnosis
- include others that patient would like to be present
- assess patients' perceptions to correct misinformation²
- giving patient as much information as desired
- letting patient set the pace of disclosure

Breaking bad news ^{ctd}

- **presenting information clearly**
- **being reassuring and empathetic**
- **encourage involvement in treatment decisions**
- **discuss patients' questions on the same day**
- **beware of overload and strong emotion**
- **provide written information/ summary**

¹Schofield P et al Annals of Oncology 2003; 14:48-56

²Mueller P, Postgraduate Medicine 2002 112(3):15-6, 18

Breaking bad news ^{ctd}

- **acknowledge and discuss patient's feelings**
- **provide realistic and honest hope**
- **assure patient of doctor's availability²**
- **summarise areas discussed²**
- **offer second appointment shortly after**

¹Schofield P et al *Annals of Oncology* 2003; 14:48-56

²Mueller P, *Postgraduate Medicine* 2002 112(3):15-6, 18

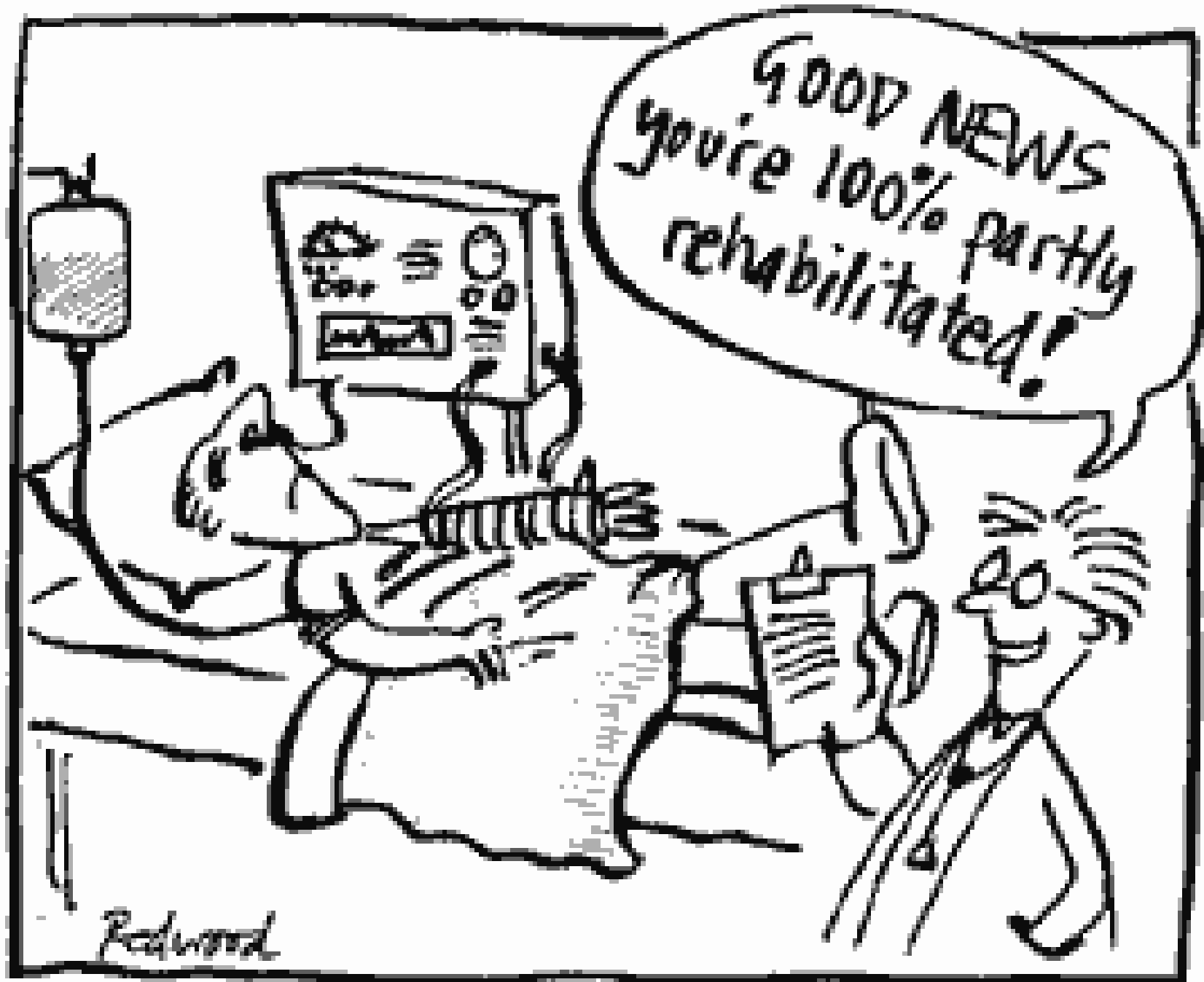
The SPIKES approach

- **S**etting up - *in private, time, place*
- **P**erception - *what does pt. know already expect*
- **I**nvitation - *what does pt want to know or share*
- **K**nowledge - *tailor to pt's level of understanding*
- **E**motions - *empathise*
- **S**trategy and summary - *check comprehension, provide a strategy for what comes next.*

Baile WF, et al. SPIKES -- A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5(4):302-11

My own practice

- **Tell patient and family together and ? then offer to see separately, or....**
- **Patient first and then family & ? then together**
- **Do it by degrees**
 - **Memory problems confirmed; test results**
 - **Age related degeneration**
 - **Disease that causes this....?**
 - **Alzheimer's**
- **Arrange follow-up for family and for patient**



GOOD NEWS
you're 100% partly
rehabilitated!

Redwood

Compassionate honesty is the best policy



- Most people want to know their diagnosis
- Attitudes over time are changing (cf cancer)
- Families often protective
- Formulae do not work
- Need to tailor information to person
- Follow-up visits/ contacts

Thank you

- www.med.unsw.edu.au/adfoap
→ Teaching → Brodaty
- www.alzheimers.org.nz
- www.alzheimers.asn.au
- www.alz.co.uk

A Shift in Attitude Toward Disclosing a Cancer Diagnosis

- **Two surveys of US physicians showed a shift in attitude toward disclosing a cancer diagnosis¹**
- **In 1961 90% would not disclose a diagnosis of cancer²**
- **In 1979 only 3% would not disclose this³**

¹Keating et al (2005). Chest; 128: 1037-1039;

²Oken (1961). JAMA; 175:1120-1128;

³Novack et al (1979). JAMA; 241: 897-900]

General Findings of Truth Telling Studies

- PWD less often told diagnosis than family members
- PWD given euphemisms (e.g. “memory loss”) more often than family members
- Family often prefer PWD not to be told, despite wishing to be told if in the same situation

Woods & Pratt (2005).

Aging & Mental Health; 9:423-429

General Findings of Truth Telling Studies

- Family feel PWD would be distressed by diagnosis and (paradoxically) that PWD would not understand diagnosis
- PWD who are told diagnosis generally feel this is preferable

Woods & Pratt (2005) Aging & Mental Health; 9:423-429

Awareness of PWD

- Pre-diagnostic counselling is considered good practice in other fields, but overlooked in dementia care
- Assumptions are made about what the PWD would want which guides diagnosis disclosure:
 - Incorrect assumptions of unawareness may then lead to distress through not knowing
 - Incorrect assumptions of awareness may lead to distress through knowing more than was wanted

Lies

- Lies may be seen as being less important in people who are unaware of what is happening¹
- 96% of care staff admit having lied to residents²
 - 88% to ease distress
 - 40% to gain compliance with treatment
 - 28% to gain compliance for other reason
 - 36% to save time
- However, “selective truth telling” is a common strategy in many areas of life¹

¹Woods & Pratt (2005). *Aging & Mental Health*; 9:423-429;

²James et al (2003). *PSIGE Newsletter*; 82: 26-28

Elson (2006) UK Survey

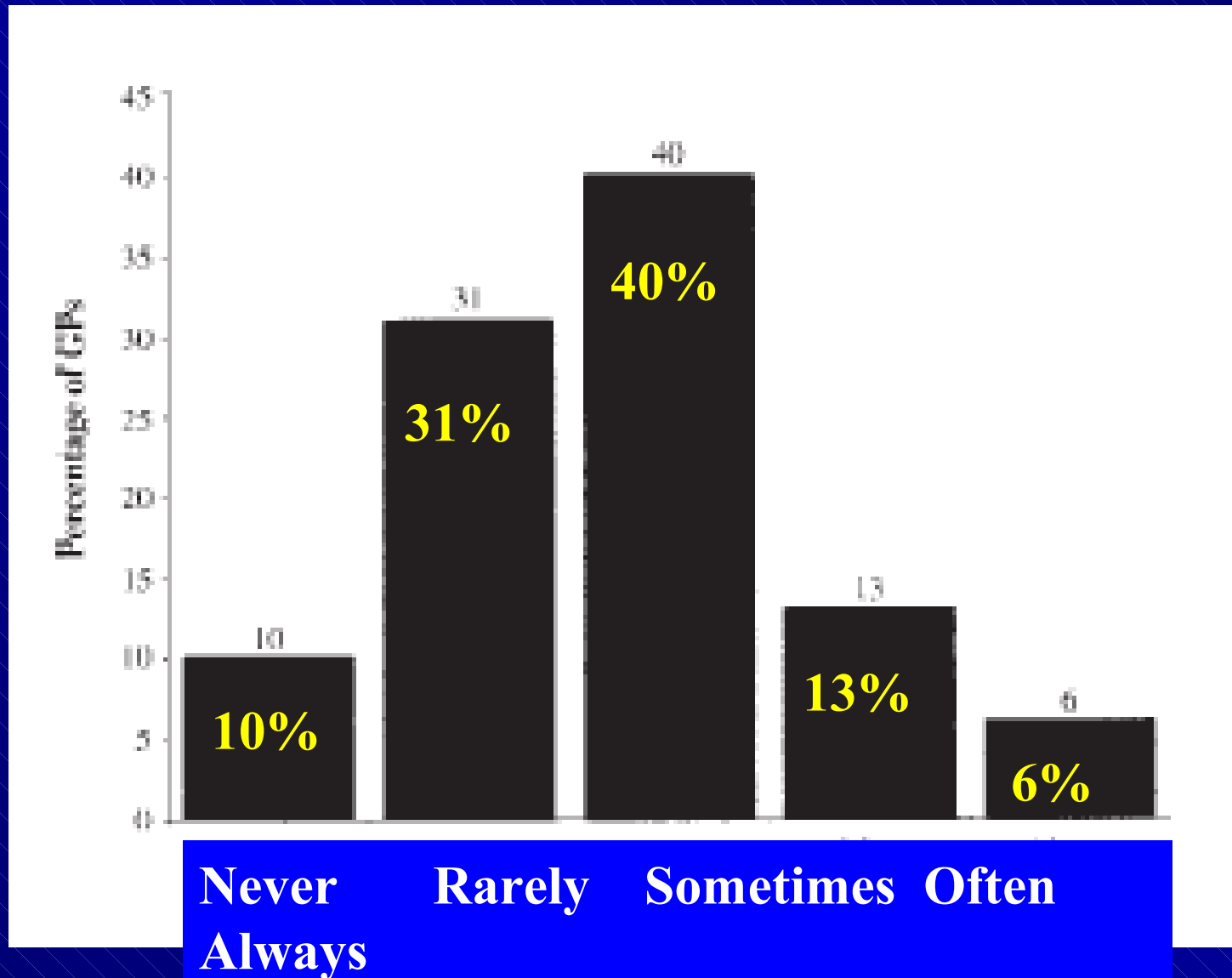
- **Survey 36 patients 65 yrs+ presenting with memory complaints to UK OAP services**
- **Majority had little understanding of the potential causes of their memory problems, however:**
 - **86% wanted to know the cause**
 - **69% wanted to know if diagnosed with AD**

Elson (2006). Int J Geriatr Psychiatry; 21: 419-425

Cahill et al (2006) Survey of Irish GPs

- **Random sample of 600 GPs from national database of 2400 - 300 useable responses**
- **Average of 4 new dementia cases diagnosed per year per GP**
- **Only 19% claimed they “often” or “always” disclosed a diagnosis to a pt**
- **38% reported their perception of the PWD’s level of comprehension as key factor in disclosure**

Frequency of Disclosure in Primary Care



CG Cultural Differences

- There may be some cultural differences in dementia disclosure by CGs:¹
 - 17%² of Irish
 - 40%³ Italian
 - 84%⁴ English
 - 100%⁵ Dutch CGs

CGs disclosed diagnosis

¹Van Hout et al (2006); ²Maguire (2002); ³Pucci et al (2003);
⁴Smith et al (1998); ⁵Dautzenberg et al (2003)

Derksen et al (2006) Qualitative Analysis

- **Semi-structured interview of 18 PWD-CG pairs about impact of receiving dementia diagnosis**
- **Disclosure impacted on 3 key domains (both PWD and CG):**
 - **Awareness of dementia**
 - **Partnership**
 - **Social relationship**
- **Most PWD and CG reported the disclosure as confirmation of their assumptions**
 - **Few felt threatened or shocked**

Derksen et al (2006). Aging & Mental Health; 10:525-531