NOTHING VENTURED, NOTHING GAINED

Jill Manthorpe & Jo Moriarty
This session is based on work we did compiling a guidance document on risk for the Department of Health

- Thinking about personal approaches to risk
- Thinking about risky situations at work
- Ways of moving from risk avoidance to risk enablement
- Presentations, group activities, and discussion
Evidence of cautious approaches to risk yet also blame cultures
- Recognition of risk as a ‘danger’ rather than a liberation

Higher eligibility requirements in terms of access to support
- ‘Managing risk’ now important than ‘meeting needs’ (Manthorpe, 2004)
WHAT WE WERE ASKED TO DO

★ Part of wider programme about the implementation of National Dementia Strategy

★ Living well with dementia (2009)

★ Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy (2010)

★ Emphasis to be on ‘risk enablement’ and ‘positive risk taking’
WHAT WE DID

1. Literature review to identify suitable material

2. Consultation with practitioners, policymakers, researchers, family carers and people with dementia

3. Guidance designed to be used for all agencies involved in supporting people with dementia
‘Risk’ seen in terms of aetiology

Most often presented in terms of ‘risk of’ developing dementia
RISK AND DEMENTIA

- ‘Link between heavy smoking and Alzheimer’s suggested’
- ‘Heavy drinking may be to blame for one in four cases of dementia’
- ‘Obesity may be linked to dementia’
FROM THE NON-DEMENTIA LITERATURE

- The role of risk perception
- Our perception of risk may be different to the technical risk

Ian Volger’s picture of Alex Jones abseiling in Trafalgar Square (Daily Mirror, 27th October 2011)
Robinson and colleagues (2007) compared the process of risk appraisal by professionals, carers, and people with dementia.

- Professionals tended to focus management strategies on the future emphasizing the physical domain of risk, for example falling.
- Family carers focussed on the present and the interpersonal domain of risk, for example loss of the partnership role.
- People with dementia appeared most concerned with the biographical domain of risk, for example, the loss of self identity.
Gilmour and colleagues (2003) compared approaches of different professionals

- Community nurses emphasised the risks of falling and not having adequate nutrition
- Social workers spoke about issues such as dealing with heating, managing money, wandering, and cooking.
- Care workers’ approach based on situated risk – a man who went for walks outside his own home was less at risk because he had neighbours who knew him and who would take him home if he got lost. By contrast, when he went into a care home he was thought to be at greater risk if he went out walking because he was in a new location situated near a main road.
We know that some people with dementia continue to drive

Practical and emotional issue

Lack of alternatives or their cost if you live outside city centres

Issues about independence and being an adult
Risk of financial abuse

- As many as 20 per cent of people under the Office of the Public Trustee in Canada (Bond et al, 2000)

- Ethical dilemmas for professionals, especially where suspected abuser is providing care (Means and Langan, 1996)

Issues about independence

Role of technology

Power of attorney
‘Risk’ seen in context of where people with dementia ‘should’ be cared for
- ‘Wandering’ and getting lost
- Safety inside and outside the home

‘Risk’ in terms of impact of diagnosis
- Efforts to increase access to memory clinics
- Advances in early diagnosis
Quick Fixes?

- Solutions focus on
  - Assistive technology
  - Legal framework (Mental Capacity Act, 2005)
- Less on strategies for family members
  - (e.g. negotiating with person with dementia)
- Less on strategies for person with dementia
  - (e.g. memory training)
Criticisms of concept of ‘risk management’

- Implies that risk can be eliminated
- Implies that all risks are negative
- Dominated by physical risks at the expense of other risks (e.g. quality of life)
Potential benefits

Potential risks or harms

Focuses on allowing the person with dementia to make own decisions where possible

Focuses on identifying the strengths that he or she has retained

Takes a more tailored approach to risk

More about *risky* situations than *risky* people
FOUR STEP PROCESS

- Step 1 – Understanding the person’s needs
- Step 2 – Understanding the impact of risks on the person
- Step 3 – Enabling and managing risk
- Step 4 – Risk planning
How much will a particular activity contribute to – or take away from – the quality of life for the person with dementia?

Balance this against the extent to which the activity might be potentially harmful to the person (or others) and so contrary to their best interests if they are not able to make the decision.
TO HELP YOU DECIDE

- Use biographical information
- Is there a statement of wishes or advance care plan?
- Who have you spoken to?
- Use Mental Capacity Act 2005 to decide on capacity
  - Social Care TV - Raymond
**STEP 2: IDENTIFYING KEY RISKS**

- Certain ‘stages’ thought to be more risky
  - On diagnosis
  - When behaviour/abilities change

- Think about impact on person if could not do versus severity of impact if something happened
Step 3: Assessing the Impact of Risk

- Personal risk portfolio or heat map
  - Balances an individual activity in terms of individual’s quality of life against the risk of harm
  - Risks of not doing something may have consequences
    - Some research supports ‘Use it or lose it’ idea
# Risk ‘Heat Map’

### Contribution to Quality of Life

<table>
<thead>
<tr>
<th>High</th>
<th>Medium</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Carefully balance safety enhancement and activity management to protect the person</td>
<td>Minimal safety enhancement necessary - carry out with normal levels of safety enhancement</td>
</tr>
<tr>
<td>Medium</td>
<td>Challenge real value of the activity to the individual - seek alternatives that are more attractive and lower risk</td>
<td>Undertake the activity or seek alternatives that may provide a better relationship with their needs</td>
</tr>
<tr>
<td>Low</td>
<td>Find alternatives - level of risk is not related to the benefit/value to the person - find alternatives</td>
<td>Substitute - can the same personal benefit be delivered in a different way - seek different activities?</td>
</tr>
</tbody>
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### Contribution to Quality of Life

- Maximise safety enhancement and risk management - protect the individual and manage the activity
- Carefully balance safety enhancement and activity management to protect the person
- Minimal safety enhancement necessary - carry out with normal levels of safety enhancement

### Risk of Harm or Reduction in Individual’s Quality of Life

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**Maximise safety enhancement and risk management - protect the individual and manage the activity**

**Carefully balance safety enhancement and activity management to protect the person**

**Minimal safety enhancement necessary - carry out with normal levels of safety enhancement**

**Substitute - can the same personal benefit be delivered in a different way - seek different activities?**

**Carefully balance safety enhancement and activity management to protect the person**

**Minimal safety enhancement necessary - carry out with normal levels of safety enhancement**

**Find alternatives - level of risk is not related to the benefit/value to the person - find alternatives**

**Challenge real value of the activity to the individual - seek alternatives that are more attractive and lower risk**

**Undertake the activity or seek alternatives that may provide a better relationship with their needs**

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**High**

**Medium**

**Low**

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**Brighton**

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Are any changes necessary?

If changes are needed, what could help make these changes easier to manage

- Assistive technology
- Assistance of support worker

Legal and ethical frameworks

- *e.g. MCA 2005*

Local policies/structures

- Risk enablement panels
# Care Plan - Example

<table>
<thead>
<tr>
<th>I value this activity</th>
<th>The risks associated with this activity are...</th>
<th>How I can enhance my quality of life</th>
<th>How will I manage the risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Playing golf</td>
<td>Being hit by ball, getting hurt, playing too long</td>
<td>Play with friend who has been briefed by wife and CPN. Take frequent rests</td>
<td>Won’t play golf without friend</td>
</tr>
</tbody>
</table>

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**BRIGHTON**
Little things contribute to our quality of life, not just ‘big’ things

- How we like a cup of tea
- Helping people with dementia to make decisions for themselves
Situations in which capacity is fluctuating

Situations in which there is a lot of disagreement

- Consensus not always possible
- Important to make sure everyone involved knows what others think
This work was funded by the Department of Health (DH) – the views are those of the authors alone and should not be necessarily interpreted as those of the DH. Thanks to all those who responded to the consultation.