NOTHING VENTURED, NOTHING GAINED DAY
29TH NOVEMBER 2011

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Jill Manthorpe
Today 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
WHY HAVE GUIDANCE?

- Evidence of cautious approaches to risk
  - 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)

- Government wants to see a reduction in ‘red tape’ and bureaucracy
WHAT WE WERE ASKED TO DO

- Part of wider programme about the implementation of 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
LOOK IN YOUR PACKS!

Which one are you?
How would you measure risk from 0 (impossible) to 10 (virtually certain)
‘Risk’ seen in terms of aetiology
Most often presented in terms of ‘risk of’ developing 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’
600% greater risk of dementia among spouses of persons with dementia than among spouses of persons without dementia.

Explanations include assortative mating, shared lifestyle, and caregiving.

Obviously needs replicating.
Corner & Bond (2004)

- interviewed 15 people without dementia as part of a wider study of quality of life and dementia
- Fear of developing dementia was a major theme for them
- Assumption that long term care was inevitable
- Assumption that only ‘basic’ care is possible because it is impossible to influence quality of life
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.
Growing literature on the role of diagnosis disclosure

People with dementia want to be told their diagnosis

It’s very important to do this sensitively

It can come both as a relief and a shock

From the Alzheimer Scotland website
ONCE YOU ARE DIAGNOSED...

- McColgan and colleagues (2000)
  - Use Goffman’s concept of the ‘moral career’ to discuss way in which Iris Murdoch’s life is presented
  - Discussed almost totally in terms of her Alzheimer’s disease once her diagnosis became known
  - People with dementia become the ‘personification of risk’ (Manthorpe, 2004)
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
Risks of falls increases with age and cognitive impairment

- Conflicts between balancing autonomy and safety
- Modifying the environment and assistive technology?
- Fall prevention strategies?
General public and media may be less sympathetic to idea of autonomy than practitioners and family carers (Robinson et al, 2007)

Distinction between ‘wandering’ and getting lost (Rowe, 2004)

Example of someone who gets lost in a hospital

– role of assistive technology, help cards, support workers
WIDER CONTEXT OF PUBLIC PREFERENCES FOR CARE

- Impact of what neighbours, general public, and other family members think
  - West and colleagues (1984)
    - Presented a series of vignettes to a random sample of people drawn from the electoral register in Glasgow
    - Vignettes presented different examples of people needing care and support
    - Long term care was always the least favoured option EXCEPT in case of the vignette depicting a person with dementia

- No recent work replicating this study
‘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
Summary (2)

- ‘Big’ issues
  - Around diagnosis
  - Around driving
  - Around money
  - Around entry into long term care
- Less on everyday issues
  - Leaving a person with dementia alone in the house
  - What to do about smoking?
SUMMARY (3)

- 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)
Think back to a risk situation for a person with dementia that you are familiar with from your own practice

- Risks identified and how it was resolved/not resolved
**RISK MANAGEMENT**

- 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)
HARM REDUCTION

- Associated with behaviours that will cause harmful consequences
  - Not a positive image for dementia
RISK BENEFIT ANALYSIS


Potential benefits

Potential risks or harms
**RISK ENABLEMENT**

- 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
Positive risk-taking is weighing up the potential benefits and harms of exercising one choice of action over another. This means identifying the potential risks involved, and developing plans and actions that reflect the positive potentials and stated priorities of the service user. It involves using available resources and support to achieve desired outcomes, and to minimise potential harmful outcomes (Morgan, 2004).
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
STEP 1: HOPES, NEEDS AND ASPIRATIONS

- 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 be have consequences
  - Some research supports ‘Use it or lose it’ idea
## Risk ‘Heat Map’

<table>
<thead>
<tr>
<th>High</th>
<th>Contribution to quality of life</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

### High

- **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

### Substitution

- **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

- **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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**Risk of harm or reduction in individual’s quality of life**

- **Low**
- **Medium**
- **High**
- **High**
STEP 4: RISK ENABLEMENT, MANAGEMENT AND PLANNING

- 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

<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>

30/11/2011

**Nottingham**
NOT JUST ABOUT ‘BIG’ ISSUES

- 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 |
GROUP SESSION 2

- Thinking about changes that we can make