'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia

DH INFORMATION READER BOX

Policy	Estates
HR/Workforce	Commissioning
Management	IM&T
Planning	Finance
Clinical	Social Care/Partnership Working

Document purpose	Best Practice Guidance
Gateway reference	14827
Title	Nothing ventured, nothing gained: risk guidance for dementia
Author	DH, Dir SCLGCP, Older People and Dementia
Publication date	10 Nov 2010
Target audience	Directors of Nursing, Directors of Adult SSs, GPs, National Dementia Strategy leads health and care services
Circulation list	Directors of Adult SSs, Allied Health Professionals, GPs, Voluntary Organisations/NDPBs
Description	Nothing ventured, nothing gained provides guidance on best practice in assessing, managing and enabling risk for people living with dementia. It is based on evidence and person-centred practice and within the context of Living well with dementia; a national dementia strategy and Putting People First. The guidance is aimed at commissioners and providers in health and care across all sectors.
Cross reference	Living well with dementia; a national dementia strategy
Superseded docs	n/a
Action required	n/a
Timing	**n/a**
Contact details	Claire Goodchild Older People and Dementia Branch Department of Health Room 304, Wellington House 135-155 Waterloo Roa d London, SE1 8UG 0789653199
For recipient's use	

The following organisations are co-signatories to *Nothing ventured, nothing gained; risk guidance for people with dementia*:

Foreword

Dementia is important to us all – as individuals, as professionals and as a society. We know from reports and predictions that the number of people with dementia is set to rise, both because of the ageing of the population and the improved rate of diagnosis. Dementia is a priority for the Coalition Government and the National Dementia Strategy sets out an ambitious, but achievable, agenda for improving the quality of life for people with dementia and their carers. The new landscape of the NHS with a focus on improved outcomes for people living with dementia provides the opportunity to take the work forward. People with dementia and their carers are supported by both health, and care – aligning these services presents a challenge at the same time as giving opportunities to maximise the synergies between them for the benefit of people with dementia and their carers.

It is a great pleasure to write a foreword to such an important document as 'Nothing Ventured, Nothing Gained'. We all face risk in our everyday lives and regularly make judgements, sometimes unconsciously, about risks and benefits for everyday actions. It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms. The trick is giving people the opportunity to live life to the full, while at the same time making sure they are properly safeguarded. This guidance provides a very helpful discourse about the issues at stake, presenting a framework for managing risk in a positive and constructive way by enabling and supporting people with dementia and their carers. I should like to congratulate everyone involved in the project in producing such a substantial and helpful document.

Alistair Burns
National Clinical Director for Dementia

Contents

List of tables and figures

About the guidance

Why it was produced

'Nothing ventured, nothing gained' is a rallying call to everyone involved in supporting persons with dementia to take a proportionate, measured and enabling approach to risk. The *National Dementia Strategy* focuses on enabling people to live well with dementia. Personalisation is about positioning choice, control and independence with the individual and it is within this context that this guidance is applied.

One of the biggest barriers to enabling people with dementia to have more control over their lives is an overly cautious approach to risk. 'Safety first' approaches are disempowering for people with dementia (Clarke *et al.,* 2009; Nuffield Council on Bioethics, 2009) and can prevent them from doing things that most people take for granted (Department of Health, 2007). They may also act as a barrier to offering people with dementia a full choice of services and support, particularly when accessing personal budgets or self-directed support (Association of Directors of Adult Social Services/Department of Health, 2009).

Using evidence from research on risk and ideas about current best practice, this guidance aims to help people with dementia, family carers, and practitioners negotiate a shared approach to positive risk taking. It is based on identifying and balancing the positive benefits of taking risks against the risks of an adverse event occurring. In this way, the best results for the person with dementia will be achieved.

Who this guidance is for

This guidance is for the use of everyone involved in supporting people with dementia using health and care services (including housing support) within any setting. These may be in people's own homes, in the community or in care homes, in primary care or in hospital, and in the public, independent or third sectors.

It cannot provide all the answers to the dilemmas faced by people with dementia, carers, and practitioners but aims to help readers reach decisions about risk so that people can carry on *Living Well with Dementia*. It does not replace any existing risk guidance, including those risk management processes contained within the Care Programme Approach, Multi-Agency Public Protection Arrangements (MAPPA), or about safeguarding vulnerable adults. Nor does it conflict with professional codes or clinical practice guidelines; rather, it provides a common

approach to risk for use across health and social care systems based on evidence from research, professionals, people with dementia, carers, and organisations. It is not about organisational risk and is primarily aimed at supporting the two thirds of people with dementia who live at home, especially those who may no longer be able to make some decisions for themselves.

How this guidance is laid out

Section A of this guidance provides a summary of the key issues relating to risk enablement and risk management.

Section B provides a review of the evidence on risk and dementia.

Section C is a framework for assessing and managing risks for people with dementia. The framework can be used to assess an individual's risks across a wide range of areas and also as a framework to assess and manage specific issues of risk or 'risky behaviours'.

Practitioners of all disciplines may wish to familiarise themselves with the evidence presented in Section B before they use the framework in Section C.

Section A: Summary

Introduction

Risk enablement, or as it is sometimes known, positive risk management, in dementia involves making decisions based on different types of knowledge. These include:

- the knowledge gained by individual people with dementia and their carers arising from their own experiences;

- practitioner knowledge, based on the collective experience and judgments of all those working in dementia services, including those involved in direct care and support who may have acquired substantial day to day knowledge about the person with dementia;

- organisational knowledge, including legislation, regulatory standards, organisational policies and procedures;

- research knowledge, based on health and social care research; and

- policy community knowledge, based on decisions made nationally and locally and including the views of think tanks and lobby groups (Pawson *et al.,* 2003).

The guidance draws on knowledge from all these sources.

Fundamentals

- Risk enablement is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether. For example, the risk of getting lost if a person with dementia goes out unaccompanied needs to be set against the possible risks of boredom and frustration from remaining inside.

- Developing systems for enabling and managing risk is one of the most important ways of allowing people with dementia to retain as much control over their lives as possible.

- Risk enablement recognises the strengths that each person with dementia possesses and builds on the abilities that he or she has retained.

- Risk enablement takes a tailored approach to risk by acknowledging that dementia affects different people in different ways. A more person-centred approach to risk and dementia concentrates upon identifying risky situations for individuals with dementia rather than viewing every person with dementia as being at equal risk.

- Practitioners should identify less restrictive alternatives – those interventions that cause less disruption or change in the circumstances of the person with dementia and which maximize their independence and freedom, with due attention to the safety of others.

- People with dementia's perceptions of risk are likely to be influenced by events and decisions that have occurred during the course of their lives, as well as by the impact of any changes that can be attributed to the effects of dementia.

- Shared *agreement* about risk will not always be possible but it is important that everyone involved in reaching decisions about risk reaches a shared *understanding* of the viewpoints of all those who are affected by decisions involving risk.

Basic ideas in risk enablement and promotion

- Risk enablement goes beyond the *physical* components of risk, such as the risk of falling over or of getting lost, to consider the *psychosocial* aspects of risk, such as the effects on wellbeing or self-identity if a person is unable to do something that is important to them, for example, making a cup of tea.

- Risk enablement plans should be drawn up which summarise the risks and benefits that have been identified, the likelihood that they will occur and their seriousness, or severity, and the actions to be taken by practitioners to promote risk enablement and to deal with adverse events should they occur. These plans need to be shared with the person with dementia and, where appropriate, with his or her carer.

- Risk assessment tools can help support decision making and should include information about a person with dementia's strengths and of his or her views and understanding about risk. The framework in Section C of this guidance includes an example of a risk portfolio.

- Knowledge and understanding of relevant legislation and guidance are important components of risk enablement. This includes knowledge of the *Mental Capacity Act 2005* and its *Code of Practice* and the *Deprivation of Liberty Safeguards* (DoLS) *Code of Practice* (Ministry of Justice, 2008).

- Risk enablement is not consistent with 'tick box' risk assessments because it is based on detailed and shared discussions among and across individuals with dementia, family carers and other supporters, and practitioners. It is an individualised approach to assessing and managing risk for the person.

Working with people with dementia and their carers

- Good practice suggests that people with dementia should be supported to remain independent for as long as possible. Risk enablement fits in well with this viewpoint.

- It is important to recognise that ideas about risk are personal and are built up over a lifetime; practitioners should try to discuss risk openly and freely with people with dementia and their carers without imposing their own values and ideas.

- Choices about risk range from major decisions, such as arranging a Lasting Power of Attorney, to making smaller decisions on a day to day basis, such as going out for a walk unaccompanied. People with dementia emphasise that being able to make small decisions on a day to day basis adds to their wellbeing and quality of life.

- While there is a 'core' of situations that are likely to apply to most people with dementia, for instance, deciding about driving, managing money, going out or being left alone independently, others might be more unusual; for example, the importance of being able to continue taking part in extreme sports.

- The most challenging time for practitioners and family carers probably occurs at the 'in between' stage when the capacity of the person with dementia to make decisions fluctuates, but is not considered to be absent altogether.

- Risk enablement plans can be developed as part of existing individual care or support plans. For example, would adaptations to the cooker help a person with dementia to cook a meal independently? Would provision of a support worker mean that a person with dementia would have someone to accompany him or her to a football match?

- Where individuals with dementia have a family carer supporting them, risk enablement assessments will probably need to be undertaken in conjunction with a carer's assessment because they impact so strongly upon each other. For example, if a family carer locks the person with dementia alone in the house

when going shopping, what practical help could be offered so that the family carer can take a break or carry out household tasks without restricting what the person with dementia can do? Where family carers are not given any support to give them a break from caring, they may end up putting their own health at risk.

Individual practice and team working

• Different professionals working with people with dementia will have responsibilities for different decisions about risk. A shared approach to risk enablement clarifies who will be responsible for what. Individuals and family carers need to know this information too.

• Panels or expert forums are one way in which professionals can ask advice and draw on the expertise of others but they should not be used as a substitute for working with individuals with dementia and family carers.

• Risk enablement plans must always be based on awareness of the capacity for the level of risk to change over time and for different types of risk to emerge. They need to be reviewed regularly because dementia is a progressive condition and the rate of change and different symptoms vary from person to person. Different subtypes of dementia may also be associated with certain types of risky behaviour. Degrees of risk will vary over time and between individuals.

Useful resources

In addition to the material presented in the evidence review, this summary draws on the following documents:

Department of Health (2007) *Best Practice in Managing Risk: Principles and evidence for best practice in the assessment and management of risk to self and others in mental health services*. London, Department of Health. Retrieved 15 June 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_ digitalassets/@dh/@en/documents/digitalasset/dh_076512.pdf.

Department of Health (2007) *Independence, choice and risk: a guide to best practice in supported decision making*. Retrieved 15 June 2010 from http://www. dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/ digitalasset/dh_074775.pdf.

Nuffield Council on Bioethics. (2009) *Dementia: ethical issues*. London, Nuffield Council on Bioethics. Retrieved 15 June 2010 from http://www.nuffieldbioethics. org/fileLibrary/pdf/Dementia_report_for_web.pdf.

Section B: Risk enablement evidence review

Choice and risk for people with dementia

"Each day brings its own catalogue of risks, some minor and some dangerous. But over time and with forgetting, there is the risk of being put on the sidelines, of being seen as a hindrance, and having control taken away from you, under the guise of it being for your own good. So, while we can, we must challenge the risks… People living with a dementia must be allowed to take risks, because if we don't, we are in danger of relaxing into the disease. At times we feel hopeless. At times the hurt we feel is indescribable and we can let it be a barrier to life. But there is a life for us, if we risk it."

(Personal account of living with dementia, Morgan, 2009, 28)

Giving people choice and control in their lives involves some element of risk and this review looks at the complex task of balancing risks and opportunities for

People with dementia are often seen as more vulnerable to risk than other people but it may be more useful to think about vulnerable situations rather than vulnerable people.

people with dementia. Health and social care organisations and professionals can sometimes face tensions between balancing risks and opportunities for individuals and their duty to care for individuals deemed to be 'vulnerable' (Taylor, 2010), employees, and the wider public (Mitchell & Glendinning, 2007;

Carr & Robbins, 2009). In the case of people with dementia, vulnerability tends to be seen in terms of increased risks to their safety, or that of others, and their risk of being exposed to abuse or exploitation. Vulnerability is a term that may be useful in indicating that a person may be at a higher level of risk from harm because of a disability or illness but instead of thinking about *vulnerable people*, it might be better to think about how people with dementia often live in vulnerable *situations*. We follow up this point later in the section on tailoring risk management strategies.

Definitions

'Risk' means different things to different people (Titterton, 2004; Mitchell & Glendinning, 2007). The way we define risk and assess its impact changes over time and in different contexts (Green, 2008). Judgements about risk are more likely to be based on social and cultural perceptions of risk than by reference to the mathematical probabilities of the risk occurring (Bond *et al.*, 2002; McDermott, 2010) so we cannot say there is a universally agreed rational definition of

> *Definitions of risk change. Terms like 'positive risk taking' and 'risk enablement' help us to take account of potential benefits as well as disadvantages when assessing risk.*

risk. Instead, we base our definitions of risk on our own experiences, values, and the factors constraining and influencing what we do (Kemshall, 2010).

'Risk' is often used interchangeably with words such as 'hazard' and 'danger' (Muster, 1997) but the Health and Safety Executive (HSE) points out that they are not the same. A hazard is an existing situation that could cause harm, such as ice on a pavement or a dangerous chemical. A risk is the chance, whether high or low, that the hazard will occur. Thus:

> A risk is the likelihood that a hazard will actually cause its adverse effects, together with a measure of the effect.
>
> (Health and Safety Executive, Undated)

The harm caused by 'adverse effects' will, of course, vary but where the harm is serious and the risks are high then a situation might be described as dangerous. In this sense, danger can be seen as something that happens when a hazard and risk are combined.

Outside extreme examples, such as exposure to certain chemicals, it has proved difficult to reach universal agreement about what constitutes danger (Muster, 1997) but one way of deciding whether a situation is dangerous is to consider whether the person with dementia is able, firstly, to recognise a hazard and, secondly, to understand its risks.

Making distinctions between hazards and risks show how risk is context-specific. Hazards may be frequent. For instance, bad weather occurs during most winters in the UK. If the effects of a hazard are thought to be manageable, then the risk

is likely to be acceptable. Later, in the section on differing approaches to risk, we present an example of a man with dementia who got lost quite frequently but nobody minded that he went out unaccompanied as many people living locally knew him and also knew where he lived (Gilmour *et al.,* 2003).

The Health and Safety Executive (HSE) definition of risk implies that managing risk involves proportionality – balancing different or competing risks against each other. Bartlett (2007) describes a man with dementia who was admitted to a nursing

> *Risk assessments need to consider the impact on people with dementia's wellbeing and autonomy as well as the possible risks to their physical safety.*

home 10 miles away from his home because of the risks posed by his 'wandering behaviour'. He then experienced loneliness because he rarely left the home or received visits from family and friends. He also felt isolated from other residents and staff because of

his gender (they were all women). The 'balancing risks' approach accepts that risk can never be eliminated completely; rather it suggests that good practice should be about acknowledging that different risks will result in a range of possible outcomes instead of unrealistically attempting to exclude them altogether (McKeown *et al.,* 1999).

Another way of looking at risk is to contrast broader and narrower approaches to risk. Broader definitions move away from negative notions of risk (Alaszewski, 1998b) towards the idea of 'positive risk taking' (Neill *et al.,* 2009) in which part of the process of measuring risk involves balancing the positive benefits that are likely to follow from taking risks against the negative effects of attempting to avoid risk altogether.

Differences between narrow and broader approaches to risk

Risk domain	'Narrow' approach	'Broader' approach
Participation in decision making	Emphasises expert judgements and technical expertise	Includes lay opinions, especially those of the person with dementia themselves and family carers
'internal incentive systems'	Focuses on individual accountability and blame with clear sanctions or negative outcomes for staff if things go wrong	Seeks to protect staff if 'true' mistakes are made, to share information and to learn (as an organisation) from mistakes or near misses

Risk domain	'Narrow' approach	'Broader' approach
'Managing the environment'	Tries to control the environment in order to take preventative action	Seeks to be responsive to risk, as almost all environments are unpredictable and are never totally risk free

(Based on: Alaszewski *et al.,* 1998):

As the following extract from Gateshead Council's (2009) *Positive Risk Taking Policy* shows, the terms *positive risk taking* or *risk enablement* are useful ways of avoiding always associating risk with danger:

> "The saying 'nothing ventured, nothing gained' makes the point that unless someone takes a risk and tries new activities, they will never know of the positive benefits that might result. In our society, people are encouraged to travel widely, take part in regular leisure and sporting activities, go to college, develop careers, and have families. These are all activities that don't just happen, but mean people have to take risks to achieve their aspirations."
>
> (Gateshead Council, 2009)

Finding better descriptions

The term 'risk management' is often used to describe the identification, assessment, and prioritization of risks. However, Cole-King and Leppina (2010) challenge the validity of this phrase, arguing that it implies risk could be eliminated if only professionals 'did it properly'. Instead they argue 'risk mitigation' is a better way of expressing professional activity. This may be a useful term to adopt in professional settings.

'Risk enablement', 'risk mitigation', and 'risk benefit assessments' are some suggestions for improving the way we talk about risk.

In its report on ethics and dementia, the Nuffield Council on Bioethics (2009) comments that risk assessments often concentrate on minimising or eliminating risk without considering what opportunities and benefits are being forgone as a result. They favoured the term 'risk-benefit assessment' as a way of explicitly taking into account the well-being and autonomy of the person with dementia, as well as their possible need for protection from physical harm.

There are many connections between terms such as risk enablement, risk-benefit analysis, and positive risk management, and they seem to be used interchangeably. Currently, they are more commonly found in professional circles so although people with dementia and family carers do weigh up advantages and disadvantages when assessing risk, they may not use these exact words to describe what they do.

Risk and dementia

Clarke and colleagues (2009, 94) point out that: 'There can be few areas of practice more complex and more contended than managing risks in dementia care'.

Understanding that different people have differing ideas about risk is an important step in reaching a shared approach to risk assessment and management in dementia support (Association of Directors of Adult Social Services/ Department of Health, 2009).

Professionals, carers, and people with dementia understand 'risk' differently. Understanding different ideas about risk is the first step in developing an effective risk mitigation strategy.

Unfortunately, the research evidence base looking at risk and dementia is still limited, except in medicine where 'risk' refers to the likelihood that a person will develop dementia. Research has tended to examine ideas about risk among professionals and carers (for example, Buri & Dawson, 2000; Adams, 2001) more often than looking at the views of people with dementia. Studies of risk and older people have provided some information when they include people with dementia or cognitive impairment (for example, Huby *et al.,* 2007) but other research on this topic has specifically excluded people with dementia.

Of course, people with dementia, carers, professionals and organisations make decisions about risk on a daily basis, meaning that there is probably more user, practitioner, and organisational knowledge about risk than there is research (Pawson *et al.,* 2003). However, this type of information is much harder to identify because it is rarely written up in formats that can be reached by a wider audience. Websites, blogs, and web forums are one way of accessing this sort of information. While our knowledge about risk and dementia needs improving, we can still find some clear messages about dementia and risk enablement.

Differing approaches to risk

Although we need more research to help us understand risk and dementia, existing studies and the experiences of people with dementia, carers, professionals, and organisations can help us in making decisions.

There are differences between practitioners' knowledge about risk and the knowledge of carers and people with dementia themselves (Clarke, 2000; Adams, 2001; Mitchell & Glendinning, 2007). Practitioners' knowledge is broad and is based on putting together information about all those individuals with whom they have worked. People with dementia and family carers have in-depth knowledge of individuals, often developed over a lifetime. This in-depth knowledge may influence the decisions they make about what constitutes risk.

Robinson and colleagues compared the process of risk appraisal by professionals, carers, and people with dementia. They found that:

• Professionals tend to focus management strategies on the *future* (Clarke, 1995) emphasizing the *physical* domain of risk, for example, falling (Alaszewski, 1998a).

• Family carers focus on the *present* (Clarke, 1995) and the *interpersonal* domain of risk, for example, loss of the partnership role (Alaszewski, 1998a).

• People with dementia appear most concerned with the biographical domain of risk, for example, the loss of self identity (Alaszewski, 1998a).

(Robinson *et al.,* 2007, 401)

Gilmour and colleagues (2003) interviewed people with dementia, carers, and professionals in Northern Ireland and found that, even among professionals, there was variation in the types of risk emphasised:

• 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.

• Family carers raised similar issues to those highlighted by social workers.

• Care workers emphasised the role of locality in managing risk. Thus, as noted above, one man who went for walks outside his own home was thought to be less at risk because he had neighbours who knew him and who would take him home if he got lost. By contrast, when the same man went into a care home for respite care, he was thought to be at greater risk because he was in a new location situated near a main road.

• GPs tended to be more accepting of risks because they balanced these against a person's desire to remain at home. However, as the research was undertaken in a rural area, GPs' attitudes may have been influenced by having known the person with dementia for longer.

At times, differing perceptions of risk may actually lead to conflicts, for example, where family members ask care home staff to ensure that a person with dementia is not allowed to leave the premises in case they get lost (Clarke *et al.,* 2009).

> "Don't get me wrong, carers are the most important people in the world but you can have carers and keepers. The latter try and assume total responsibility for your life prematurely, and there are many of them around."
>
> (Peter Ashley, Person with dementia)

Assessing risk

From the perspective of people using services and carers, professionals may base their decisions about risk on generalised assumptions about the capacity or 'riskiness' of certain groups without finding out more about individuals and their circumstances (Carr, 2010). Although dementia often gives rise to concerns because of difficulties with memory, functioning and dealing with the risks of everyday life (Manthorpe, 2004), people with dementia are not all at equal risk. Some sub-types of dementia, for example frontal lobe dementia, are more associated with certain type of risky behaviour than others, such as Alzheimer's disease (Mendez *et al.,* 2008).

Understanding which risky situations might occur and how much the person with dementia understands about these risks is part of the process of 'naming' and defining risk which avoids either seeing people with dementia as the 'personification of risk' or attempting to manage risk by denial and 'sweeping it under the carpet' (Manthorpe, 2004, 148).

Decisions about risk should not assume that all people with dementia are 'at risk' but should be based upon understanding of individuals and their own understanding of the risks they may face.

Two studies show that while risky or dangerous behaviour is common in dementia it is not universal. In one UK study (Walker *et al.,* 2006), family carers reported that just over two thirds of a sample of family carers thought that the person for whom they cared had been 'at risk' in the past year, although they attempted to minimise these occurrences through supervision and other safety strategies. The researchers viewed these concerns as realistic and thought that they were not influenced by family carers' own anxieties or levels of stress.

The other study took place in Argentina and consisted of people with Alzheimer's disease or probable Alzheimer's disease, attending a clinic who were compared with a 'control' group of volunteers without the condition (Starkstein *et al.,* 2007). Family carers reported that 16 per cent of the people with dementia had shown dangerous behaviours in the previous month, compared with two per cent in the control group (Starkstein *et al.,* 2007). However, 50 percent of the people with Alzheimer's disease or probable Alzheimer's disease had a poor

Finding out more about how much a person with dementia knows about dementia and its impacts could be one way of helping him or her to reach decisions about risk. Risk enablement strategies need to identify the likelihood of the risk and its seriousness.

awareness of danger (Starkstein *et al.,* 2004). Family carers supporting people with mild to moderate Alzheimer's disease reported this more frequently than those

caring for those who were more severely affected. Behaving dangerously was associated with lack of awareness of having Alzheimer's disease or denying that they were affected (anosognosia) (Starkstein *et al.,* 2004; Starkstein *et al.,* 2007).

Bond and colleagues (2002) warn that we should not assume people with dementia lack insight without making any objective assessment of whether they are able to make decisions in day-to-day situations. Otherwise, we may exaggerate or underestimate the risks they pose to themselves and to others and reduce their autonomy and quality of life.

Taken together, these studies highlight the importance of:

- taking an individualised approach to risk and dementia;

- finding out what people with dementia know about dementia and its impact instead of making assumptions about what they know; and

- trying to find practical strategies to address the concerns of family carers and professionals.

Potential or emerging risks

For some people with dementia, the risks of mistreatment or abuse may be emerging, rather than actual. Like all risks, these need to be specified. Is the person at risk of theft because they open the door to strangers or to young people who are using their home for drinking or taking drugs? Or is the person with

> *Risk or harm mitigation strategies need to identify the likelihood of risk and its seriousness.*

dementia at risk of neglect or even mistreatment in a busy care home that is short-staffed? In their study of professional decision making, Taylor and Donnelly (2006) report that fear of crime was an important factor influencing professionals' judgement about whether or not to recommend entry to care homes for older people, many of whom had dementia. In the busy care home, a risk approach might specify the potential for overlooking a quiet individual whom members of staff think wants to be left alone. In instances such as these where actual instances of risk cannot be recorded easily, one key part of a risk or harm minimisation strategy could be the inclusion of risk management approaches to cover areas that are giving rise to concern in care plans for a person with dementia. These need to identify the likelihood of the risk and its seriousness. Such plans have to be personalised and would, of course, need to be monitored, and reviewed regularly.

Safeguarding and risk

We know little about the risks of abuse experienced by people with dementia and so there is little to guide practitioners about effective approaches. We know from tragedies and scandals in care and health services that some people with dementia are subjected to poor care but we are less clear how much of this arises from their dementia or from other disabilities and their living situations. This is

not to underestimate the severity of these issues; rather to highlight that risk management strategies might focus more on the identification of those at risk rather than assume that everyone has an equal chance of being affected.

One key point for practice is that instead of using the word 'risk' we may be better able to ensure that support is addressing the real problem if we start to think of the 'risk of?' approach. In the example above, the busy care home might lead to different risks for different residents, some quiet residents might be at risk of being neglected; others might be at risk of 'rough handling' if they are very slow or seemingly uncooperative with care.

Promoting independence

Although there is little research from which to draw clear conclusions on specific interventions aimed at promoting independence, the NICE-SCIE dementia guidelines (National Collaborating Centre for Mental Health, 2006) concludes that it is good practice to promote independence at all stages of dementia.

Promoting independence is a way of minimising risks and maximising opportunities for people with dementia.

Advice from the Alzheimer's Society (2008d) suggests that memory aids and other reminders can help a person with dementia to retain their skills for longer. These may be of most help in the early stages of dementia when the person is better able to understand the message and to act upon it. Ideas include:

• labelling cupboards and drawers, perhaps using pictures rather than words – for example, a photo of a cup and jar of coffee;

• a large calendar showing the day, month and year;

• a notice board for messages; and

• notes stuck by the front door.

(Alzheimer's Society, 2008d, 3)

Enabling a person to keep their skills may seem on the face of it to present some risks but there is consistent advice that staying active as long as possible avoids adding to distress or anxiety and contributes to the person with dementia's quality of life.

Tailoring risk enablement strategies

Listening and negotiation skills are important to risk enablement. Listening skills help identify which issues are most important to people with dementia and family carers. Negotiation skills are needed to reach a shared understanding about risk.

What people with dementia think about risk

Gilmour and colleagues (2003) comment that none of the nine people with dementia they spoke to used the word 'risk', although six of them referred to frustrations caused by problems with their memory.

Research with people with dementia (Pratt & Wilkinson, 2003; Robinson *et al.,* 2005; Harris, 2006; Lu *et al.,* 2007; De Witt *et al.,* 2009) shows that they often experience a sense of loss and develop strategies to help them deal with the changes they are experiencing. These act as a way of self regulating risk, such as giving up certain activities or hobbies that they feel they are no longer able to do.

> *Avoiding jargon and using similar language to the person with dementia helps identify how individuals define and assess risk. This takes time and is unlikely to be found out in 'tick box' assessments.*

At the same time, people with dementia may take a sense of pride and achievement in focusing on those abilities that remain. In this sense, discussions with people with dementia that are based on the skills they have retained and the 'ways they get round problems' are likely to be more effective than using terms that might be perceived negatively, such as being 'unsafe' or 'at risk'.

As with other groups of people using health and social care services, the concepts of independence, choice and control are important for people with dementia (Aggarwal *et al.,* 2003; Harris, 2006). However, 'there are many people for whom self-esteem is not predicated on independence' and there may well be cultural differences in approaches to risk that need to be considered (Woods, 1999, 97). Sensitive approaches to risk also need to consider that even within dementia care there are 'taboo' areas, such as sexuality, about which people are sometimes reluctant to talk (Innes *et al.,* 2004). In this sense, people with dementia and family carers may find it easier to talk about certain types of risk than others.

Narrative and biographical approaches to risk

'Lives, like stories, have a trajectory through time. What comes before affects – and to some extent determines – what happens next' (Baldwin, 2005, 1023).

The use of biographical and life story work has a long history in dementia care (Williams & Keady, 2006), although the opportunities for people with dementia to express themselves by telling their story may be limited (Baldwin, 2008). Living with, and making decisions about, risk

> *Life stories and other biographical approaches can help establish how people with dementia have developed an approach to risk over their lifetime.*

can make up a major part of older people's lives (Bornat & Bytheway, 2010). A willingness to take risks can be a crucial part of a person's sense of self-identity

(Tulloch & Lupton, 2003) and a US study of university students (Wang *et al.,* 2009) suggests that people's propensity to take risks is influenced by their life history. With this in mind, one aspect of tailoring risk enablement strategies would be to consider how individual people with dementia have taken differing approaches to risk throughout their lives using life story and biographical techniques (see Life Story Network, Undated). Life story techniques may be undertaken by a range of practitioners, often in combination with family carers.

Developing shared understandings of risk

In his study of community psychiatric nurses (CPNs) and risk, Adams (2001) describes a four stage process by which CPNs encouraged family carers to talk about risk:

- 'fishing' – making a statement about risk that enabled carers to talk about situations that related to their relative's care;

- identifying the risk;

- risk assessment; and

- risk management.

Alongside other researchers and commentators (Bond *et al.,* 2002; Mitchell & Glendinning, 2007; McDermott, 2010), he highlights the socially constructed way in which risk is defined as well as highlighting the time needed to establish a shared approach to managing risk.

Professionals with backgrounds in nursing, social work, occupational therapy and teaching working for a dementia monitoring programme who were interviewed as part of an Australian study (Waugh, 2009) considered that two factors were key to making decisions about risk:

- their knowledge of, and relationship with the person with dementia; and

- shared discussions with the person with dementia, families, neighbours and other professionals.

Shared approaches to risk are needed to avoid misunderstanding and clarify which decisions have been taken. Shared approaches may not always result in shared agreement but it is important to establish who thinks what and why.

Gilmour and colleagues (2003, 414) give an example where failure to have this sort of discussion resulted in resources being wasted. A social worker arranged for a family to be provided with a hoist only to find that it remained unused because the family thought it would be 'degrading for their mum' and the bedroom would have to be completely rearranged.

Clarke and colleagues (2010) describe the process by which people with dementia, family carers and professionals become members of a 'triad' or triangle negotiating seeking to moderate each other's perceptions of risk, and explain and reconcile the changing dynamics of their relationships. In contrast to some approaches to risk that only look at major decisions, such as those being considered when drawing up a Lasting Power of Attorney, such as selling a house, agreeing to an operation, or moving to a care home, the 'contested territories' of everyday living with dementia identifies areas such as friendships, smoking, going out, domestic arrangements, and occupation and activity. Taking time to negotiate these aspects of everyday living is particularly important where principles such as autonomy and preventing harm may be thought to conflict (Hughes & Baldwin, 2006). This also applies to the 'small acts of care' undertaken in care homes and home care services (Stanley & Manthorpe, 2009).

Seeking advice

Even in the context of trusting relationships and familiarity with a situation, making decisions about risk can be difficult and organisations and practitioners can feel vulnerable about the risks they may face if they make a decision which turns out badly (Taylor, 2006; Clarke *et al.,* 2009). Sharing a risk assessment with a range of people with different backgrounds and experiences may be more helpful than just talking about it with a group of colleagues who often share the same views and values. Some organisations (for example, London Borough of Newham, 2009) have created panels or forums to provide advice in the case of complex risk decisions. However, the effectiveness of these developments has yet to be evaluated.

Legal framework

Mental Capacity Act 2005

In England and Wales, the *Mental Capacity Act* (2005) (MCA) provides a much needed framework for making decisions and for setting out a person's wishes about what they wish to happen if their ability to make decisions is impaired. There has been much interest in the ways in which people can set out decisions

> *The* Mental Capacity Act 2005 *provides a framework for decision making.*

about care and treatment but far less about the potential for people to use the provisions of the Act to set out their wishes in advance. This can include writing down their views of what they think they would like to happen in certain circumstances. This information is useful to practitioners in providing them with some evidence of what a person previously valued or wanted to happen. Some of this might cover serious risks, but a sense of what people might like to happen to

them has sometimes been lacking for practitioners, particularly for people who no longer have family or friends (see Samsi & Manthorpe, 2010). Having this knowledge can help provide a better quality of life for people with dementia:

> Peter also has an advanced directive which, as well as stipulating the kind of medical care covers a range of quality of life issues (I don't like baths, I like showers…I don't want to watch TV all day…). "It deals with the more obvious things in life that I hope might make me happy when I lose some of my intellectual competence."
>
> (Peter Ashley, quoted in Robins, 2010)

Even in the absence of a formal statement of wishes or advance care plan, people's views and wishes – whether written down or not – may be used to assist in planning support for them and making decisions in their best interests if they are no longer able to make decisions. Such statements of wishes and feelings are important, particularly if they are written down, but are not legally binding in the same way as advance decisions to refuse care and treatment.

Another part of the *Mental Capacity Act 2005* enables anyone to draw up a Lasting Power of Attorney (LPA). Here an individual can, while they still have capacity, appoint another person (known as an Attorney) to make decisions on their behalf about financial, welfare or health care matters. The person making the LPA chooses who will be their attorney – it can be more than one person. They can allow the attorney to make all decisions when the power is registered or they can choose which decisions they can make. So, for example, a person with dementia may appoint a relative or partner because they believe that this person will be able to defend their interests or ensure that their particular priorities are respected as far as possible. In the example below, it may be that Sanita recognises that her mother will be at risk of not having her care needs fully met if she does not move:

> Mrs Singh has been a resident of Ivy House, a care home, for the last five years. The manager of the home thinks that she should move from the residential side of the home to the nursing part of the home as her disabilities have increased and her needs can no longer be met by the residential care section. Funding is available for the transfer but Mrs Singh does not appear to understand what the manager is telling her. Some time ago, Mrs Singh asked her daughter Sanita to act as her attorney to make decisions about personal welfare and healthcare (this was registered with the Office of the Public Guardian on the prescribed form). When the manager talks to Sanita about the situation, Sanita tells the manager that she can make the decision on her mother's behalf because she is an attorney for her mother.
>
> (Department of Health/Welsh Assembly Government, 2007, 45)

Other parts of the *Mental Capacity Act 2005* mean that professionals may be called upon to help a person with dementia where there is no prior legal arrangement in place for one person to make decisions on behalf of another. Court appointed deputies are professionals or lay people appointed by the Court of Protection to make decisions on behalf of an 'incapacitated' adult in their best interests. This would take place, for example, where no LPA exists or there is

> *People with dementia should be encouraged to make as many decisions as possible for themselves using the five core principles of the* Mental Capacity Act 2005*.*

a serious dispute amongst family carers. These frameworks may help ensure that better risk assessments are carried out; particularly if people abide by the principles of the *Mental Capacity Act 2005*. The underlying philosophy of the *Mental Capacity Act 2005* is to ensure that individuals who lack capacity are the focus of any decisions made, or actions taken, on their behalf and all decisions about mental capacity should be guided by the five Core Principles of the *Mental Capacity Act 2005*. This means that an individual approach which centres round the interests of the person who lacks capacity, not the views or convenience of those caring and supporting that person, should prevail. Staff and family carers should make every effort to ensure that people with dementia are helped to make as many decisions as possible for themselves.

Five Core Principles of the *Mental Capacity Act 2005*:

1. A person must be assumed to have capacity unless it is established that they lack capacity.

2. A person is not to be treated as unable to make a decision unless all practicable (doable) steps to help him to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

(Mental Capacity Act 2005)

The Nuffield Council on Bioethics comments that the most difficult situations arise in borderline decisions:

> In many cases, it will be very clear whether a person with dementia does or does not have the capacity to make a particular decision. However, there will be times when the person's ability to make a particular decision will be difficult to determine. The implications for the individuals concerned are potentially very significant: if they are assessed as having capacity they will be free to choose their own course of action (even if regarded by others as highly risky), whereas if they are assessed as lacking capacity their wishes may be over-ruled by others in the hope of protecting their best interests.
>
> (Nuffield Council on Bioethics, 2009, xxii)

However, there are a number of accounts emerging of how the Mental Capacity Act 2005 may be providing a better framework for practitioners in seeking to enable people with dementia to take risks. In one example of practice with an older man with dementia living in sheltered housing who liked to go out for a walk, a social worker recalled:

> "I have spoken to the son… We doubt that [his father] has the capacity to make that decision but it gets him out, lends structure to his day, it gets him socialising… When I last visited [the father] his scheme manager said… 'This chap isn't safe anymore, he needs to go into a residential home'… but when I explained to him, the scheme manager… 'this is why it is in his best interests' – he couldn't argue with it, whereas I don't think I would have had that argument two years before the Act came out".
>
> (Manthorpe et al., In press)

Deprivation of liberty (DoLS)

There is no simple definition of deprivation of liberty. The question of whether the steps taken by staff or institutions in relation to a person amount to a deprivation of that person's liberty is ultimately a legal question, and only the courts can determine the law. The Code of Practice (Ministry of Justice, 2008) offers guidance and a link to this guidance is included in the references.

The European Court of Human Rights (ECtHR) has drawn a distinction between the deprivation of liberty of an individual (which is unlawful, unless authorised) and restrictions on the liberty of movement of an individual. The difference between deprivation of liberty and restriction upon liberty is one of degree or intensity. The ECtHR and UK courts have determined a number of cases about deprivation of liberty. Their judgments indicate that the following factors can be relevant to identifying whether the steps taken involve more than restraint and

amount to a deprivation of liberty. It is important to remember that this list is not exclusive; other factors may arise in future in particular cases:

• Restraint is used, including sedation, to admit a person to an institution where that person is resisting admission.

• Staff exercise complete and effective control over the care and movement of a person for a significant period.

• Staff exercise control over assessments, treatment, contacts and residence.

• A decision has been taken by the institution that the person will not be released into the care of others, or permitted to live elsewhere, unless the staff in the institution consider it appropriate.

• A request by carers for a person to be discharged to their care is refused.

• The person is unable to maintain social contacts because of restrictions placed on their access to other people.

• The person loses autonomy because they are under continuous supervision and control.

Further legal developments have occurred since this guidance was issued, and healthcare and social care practitioners need to keep themselves informed of legal developments that may have a bearing on their practice. Within local councils the manager with responsibility for DoLS or the MCA will be the best source of advice and information.

Guidance on reporting deaths to the coroner

We are extremely grateful to Professor Paul Marks for his assistance with this section.

Each person with dementia experiences their illness in their own individual way (Alzheimer's Society, 2010c) but in its advanced stages dementia is essentially a terminal condition (Mitchell *et al.,* 2009). There may be particular anxieties about promoting risk enablement if fears of the reporting and investigatory processes surrounding investigations of serious harm or death result in overly risk averse decisions. Essentially, the same rules with regard to death certification apply to people with dementia as they do to others. In most circumstances, the Medical Certificate of the Cause of Death will be completed by a registered medical practitioner pursuant to s 22 of the *Births and Deaths Registration Act (1953)* to his or her *best knowledge and belief*.

If a case is referred to the Coroner because the person who has died had not seen a doctor in the previous 14 days or has been seen after death, the Coroner, following consultation with the deceased's medical attendant, may not need to order a post mortem examination and the case can be disposed of via Coroner's 'pink' form A (which is orange).

If a post mortem is carried out and shows that death was due to natural causes the Coroner will issue notification of this on Coroner's pink form B (form 100). This enables the death to be registered and, if disposal of the body is by cremation, the Coroner will also issue cremation form 6.

If an inquest is held it is the Coroner's duty to establish at inquest **who** was the person who has died as well as **how, when** and **where** the death came about. Following the inquest, the Coroner will send the necessary details to the Registrar of Births and Deaths for registration purposes.

Deaths should be referred to the Coroner under the following circumstances:

- Where the cause of death is unknown.

- The deceased has not been seen by a certifying doctor either within 14 days before death or after death.

- When death was violent, unnatural or suspicious.

- Where death was due to an accident (note that no time limit is set for this even if there is an interval of, for example, 25 years or more between the accident and death).

- Where death might be due to self-neglect or neglect by others.

- Where death is a consequence of industrial disease.

- Where death is related to abortion.

- Where death occurs following surgery or recovery from anaesthesia.

- Suicide, for example, overdose, trauma from jumping from a building and so on.

- Death following detention in police custody or prison or shortly thereafter.

Issues relating to neglect or self-neglect may be relevant to the scope and purpose of an inquest. Furthermore, where deaths occur in hospital or a care setting, the circumstances may be such that a procedural duty arises to engage Article 2 of the European Convention on Human Rights, which effectively extends the scope of the inquest.

Defensible decisions

Research has shown that anxiety about the consequences of decisions about risk is a major concern for practitioners (Taylor, 2006) and that fears about coroners or management reviews can be high. Given that it is impossible to eliminate risk from people's lives, practitioners may need to defend their decisions about risk. This is especially important in circumstances where people with dementia, the main family carer, professionals, and care providers may have reached decisions about risk but other family members do not agree with these decisions.

An action or decision is deemed defensible if an objective group of professionals would consider that:

• all reasonable steps have been taken;

• reliable assessment methods have been used;

• information has been collated and thoroughly evaluated;

• decisions are recorded, communicated and thoroughly evaluated;

• policies and procedures have been followed; and

• practitioners and their managers adopt an investigative approach and are proactive.

(Kemshall, 2009)

The final part of this evidence review discusses some common situations in which decisions about risk are needed.

Dealing with diagnosis

People with dementia often want to be told their diagnosis (Pratt & Wilkinson, 2003; Robinson *et al.,* 2005), especially because finally having an explanation of the difficulties they have been experiencing can come as a relief (Carpenter *et al.,* 2008).

> "I was relieved really that what I was trying to convince people of had been verified."
>
> (Person with dementia, Department of Health, 2009, 31)

People with dementia want to be told their diagnosis but they want to be told it with sensitivity and for it to be accompanied by promises of support.

Nevertheless, there are disadvantages as well as benefits to receiving a diagnosis (Iliffe & Manthorpe, 2004; Milne, 2010), such as stigma and loss of status. Iliffe and Manthorpe (2004) suggest that a risk assessment approach to the process of disclosure of diagnosis is needed. This is partly because confirmation of diagnosis can come as a shock, even if it is followed by a sense of acceptance:

"I was in utter shock for the six months after my diagnosis. My wife and I felt we had hit rock bottom and I thought there was nothing worth living for. But then I came to a point, which I now think of as 'my resurrection'. I decided that I would make the best of my life until the worst of the disease comes along."

(Peter Ashley, quoted in Age Concern, 2008, 33)

Family carers may also be affected:

"When the formal diagnosis of vascular dementia was made, my feelings were of devastation and catastrophe. I was overcome with a deep fear for the future, as well as deep sorrow and sympathy for my husband".

(Debbie, in Whitman, 2010, 54)

A Danish study (Erlangsen *et al.,* 2008) reports an increased risk of suicide among people with dementia, especially in the first three months following diagnosis. It has been suggested (Draper *et al.,* 2010) that suicide may occur more frequently with the trends towards earlier diagnosis. This process could be improved even further if there is further progress in identifying a 'preclinical dementia phase' (a period in which cognitive changes occur prior to clinical diagnosis) (Elias *et al.,* 2000) and in developing biomarkers (biological indicators whose presence indicates that a person will develop a disease in the future) (Wright *et al.,* 2009).

The sensitivity with which disclosure of diagnosis is made is important and people with dementia and their family carers give a mixed picture about how well this is done (Lecouturier *et al.,* 2008). Sadie Bowie from the Scottish Dementia Working Group remembers:

Anyway, after the first scan at the hospital, I went to get the results. It turned out to be dementia. I heard the news – I was on my own. I came out into a waiting area that I remember as being a horrible drab place and just sat there. I didn't know what to do or say. I called one of my friends and then jumped on the first bus I saw and just sat there deep in my own thoughts totally unaware of where I was or in what direction the bus was going.

(Bowie, 2009)

However, there is some agreement about the components of good practice in disclosing diagnosis. These include: taking a stepped approach to disclosure so as to ascertain a person's desire to know and exploring his or her reactions to diagnosis, involving family members if possible; emphasising that progression is slow and that quality of life is possible, and offering ongoing support (Lecouturier *et al.,* 2008; Draper *et al.,* 2010). A range of factsheets (Alzheimer's Society, 2010a) are available to support people who have been recently diagnosed, as well as a leaflet written by people with dementia (Alzheimer Scotland – Action on Dementia, Undated). Support groups for people with dementia many also be beneficial (Cheston *et al.,* 2003; Aminzadeh *et al.,* 2007).

> *Not all professionals will be involved in the process of diagnosis disclosure, but everyone needs to know how much the person with dementia knows about their condition so they can answer questions honestly and openly.*

Managing money

Managing money can cause concern to people with dementia and their family carers (Gilmour *et al.,* 2003; Walker *et al.,* 2006). Changing the way that finances are organised can help:

> I had always liked to pay by cash but I arranged direct debits as much as possible. I changed my bank account into a joint account: this was quite traumatic and the big risk here is trust. These changes will make it easier for the future. Yet despite these positives, they hand risk back to you. I have a bank card, a password, and a pin number to remember. I can't use it if/when I forget it.
>
> (Morgan, 2009, 28)

At the same time, as well as finding ways of reducing risk, it is also important to recognise the circumstances in which people with dementia have the right to make unwise decisions about their expenditure. In a fictional example of an encounter between Raymond and his care worker (Social Care Institute for Excellence, 2009b), the care worker ultimately agrees to Raymond's request to buy him some lottery tickets but not before making it clear that she feels this is an unwise use of money. She makes sure that she also records what has happened.

> *Carers and care workers may be faced with difficult decisions when dealing with day to day decisions about how people with dementia spend their money. Discussing these issues and recording what decisions are made helps protect workers and carers from worries that they will be accused of financial abuse.*

There is a fine line between deciding what is unwise, but legitimate, decision making and what is not, which is why, as we suggested earlier, sharing a risk assessment with a range of people with different backgrounds and experiences may be helpful.

The section on Legal Frameworks explained that people with dementia who make arrangements about their future support needs while they still have capacity may reduce the risk that, in the future, their financial affairs will not be managed in a way that they would have chosen (Alzheimer's Society, 2009). While a Lasting Power of Attorney may be one way to secure this, day to day decisions about money can give rise to very troubling situations.

There are safeguards in the *Mental Capacity Act 2005* for staff making decisions on behalf of people who lack capacity, providing they have undertaken the current procedures. Other examples might include providing a person with some cash, even if it goes missing. Risk assessment in these circumstances can help promote the dignity of a person with dementia. It is good practice for staff to be informed about risk assessments and the management of risks; in the example below, for instance, another member of staff might worry about the possibility that Esther is being financially abused:

Following a discussion with the home manager, staff make a best interests decision on behalf of Esther, a care home resident with severe dementia, when they buy a Christmas present for Esther's daughter out of Esther's personal allowance as she asked them to do but could not remember what her daughter liked. They used to do this in the past when Esther was able to ask them to buy her daughter her favourite soap. They keep the receipt, give it to the home administrator, and write down what they have done in Esther's file. As they have sufficient information to explain why and what they did, staff will be protected if anyone asks why they bought such an expensive soap.

(Department of Health/Welsh Assembly Government, 2007, 25)

Driving

In the UK, if someone receives a diagnosis of dementia and wants to continue to drive, they must, by law, inform the Driver and Vehicle Licensing Agency (DVLA).

Some people with early dementia are thought to be capable of driving safely for a period of around three years after the disease becomes clinically apparent, depending on individual circumstances (Breen *et al.,* 2007). It is thought that this period may increase with more accurate screening methods for earlier diagnosis (Dawson *et al.,* 2009). Driving is very much related to independence and

GPs, clinicians, and carers can face difficult ethical dilemmas if a person with dementia wants to continue to drive. Resources such as support groups for people with dementia and factsheets can help people with dementia make decisions about driving.

adulthood and so decisions about when, or if, people with dementia should give up driving can become contentious (Harris, 2006). Family carers often face difficult ethical dilemmas about what to do in these circumstances (Hughes *et al.,* 2002). This also applies to clinicians and general practitioners, given that the DVLA bases its decisions on the basis of medical reports, because they must balance the potential risks created if a person with dementia continues to drive made against the risks to his or her quality of life if they give up driving (Naidu & McKeith, 2006). This decision may be especially difficult where the person with dementia lives in an area where public transport links are poor.

Factsheets on driving (for example, Alzheimer's Society, 2008c) offer a concise guide to the topic and can be used to help people with dementia reach a decision about when to give up driving. Support groups are another source of advice:

> "I have given up driving. I realised that it was necessary even though it was a very difficult decision. My partner tells me that I am now a terrible back-seat driver!"
>
> (Nigel, quoted in Alzheimer Europe, 2009)

> "I immediately contacted the DVLA. This led to a full declaration of everything and not only taking my condition into consideration but also my age it was decided I would have to undertake a comprehensive driving assessment…far worse than a normal driving test but handled with great sensitivity by those concerned…The result is I have a reaction time half that of most drivers, a clean assessment record, and I have a full licence to be reviewed each year. But more importantly I have peace of mind…Do I drive all the time? No…I do so when it's absolutely necessary and I feel well enough, but it's my decision."
>
> (Peter Ashley, Person with dementia)

"I think the biggest challenge in my life is I'm fearful of driving and at my last [support group meeting], we talked about driving. The leader conscientiously pointed out that I'm really putting myself at risk. And I have been thinking about it that I want to stop." In a follow up interview 4 months later, she stated that she had stopped driving.

(Harris, 2006, 90)

Managing social care

Changes occurring in the social care systems in England are considerable. Often 'badged' as personalisation or self-directed support, these changes have the

People with dementia lacking the capacity to consent to direct payments are now able to receive them. Department of Health guidance gives advice on how to manage this process.

potential to improve the quality of support for people with dementia. With a personal budget, for example, a person may be able to secure reliable home care support, employing a particular worker who will get to know him or her, support her to do what he or she wants, and the support plan agreed with the local authority will include what might happen if the care worker was ill or there was a sudden need for extra support (Manthorpe, 2009). Research (Glendinning *et al.,* 2008) among people who received an early form of personal budget (an individual budget) found that older people tended to spend more of their allocation on support workers and less on traditional services such as day care.

Since November 2009, the system of direct payments (cash for care) has been extended to include those who lack the capacity to consent to the making of direct payments. The guidance (Department of Health/Department for Children, Schools and Families 2009) accompanying these regulations explains how direct payments services should be developed locally, how issues of consent, capacity and ability to manage should be approached and how direct payments should be used. It sets out specific delivery issues, explains where additional support is required and available, and describes the monitoring and review process. It also includes a section on troubleshooting or managing specific risks. The risks of direct payments, where people receive money to pay for care and support, appear low but there is not much research evidence on this topic available yet. While devising a support plan is one thing, we know little about how best to monitor them, so that aspirations for greater choice and control do not just remain on paper.

When local authority staff are concerned about risks relating to direct payments, they may propose a managed personal budget as an alternative; where the contract remains with the local authority, which either directly provides services

or arranges them with a third party provider. The individual knows the sum of money allocated and is given as much choice and control over services provided as is reasonable and appropriate. Alternatively, the local authority may impose conditions on a direct payment, for example by insisting that there is some independent regular contact with the person with dementia to ensure their wellbeing or only allowing the direct payment to be used to pay care workers who have had Criminal Record Bureau checks. We have little indication of yet how this works but it appears to be a sensible approach taking into account the nature and level of potential risk.

There is scope for support plans to be made more often by people with dementia and their family as they are the experts in the situation. The *Dementia Choices* project (Mental Health Foundation, Undated) is examining how local authorities are exploring, supporting and promoting different forms of self-directed support, including direct payments, for people living with dementia and their family carers.

Assistive technology and risk enablement

Assistive technologies can support independence and enable people with dementia to live in situations, or take part in activities, that might otherwise be deemed to be risky. Resources such as *at dementia* (at dementia, Undated) or Alzheimer's Society (2008b) bring together information about the assistive technologies which are available. Some individuals with dementia and their family carers have found devices such as bed occupancy sensors, which can detect

> *A number of assistive technologies exist which can help improve safety for people with dementia but more research is needed on their effectiveness and cost effectiveness.*

when a person with dementia has fallen out of bed or left the room; sensors that can detect extremes of temperature; and property exit sensors, which can tell if a person has left their home, extremely helpful. However, others may see such technologies as intrusive and a threat to privacy (Robinson *et al.,* 2007; Powell *et al.,* 2010). Assistive technologies should not be used without discussion or consideration of these issues. Systematic reviews (Martin *et al.,* 2008; Powell *et al.,* 2008) also caution that we need more evidence on the results of using assistive technologies and their cost effectiveness.

Low-tech solutions such as improved lighting, adaptations such as bath aids (Alzheimer's Society, 2008e, 2008a) and environmental design (Dementia Services Development Centre, 2007) should not be forgotten as they can also help increase autonomy for people with dementia and mitigate risks.

Walking safely and going outside

In the past it was common to refer to 'wandering' but the terms walking or safe walking are now preferred as they reflect the fact that 'wandering' is not a term used by people with dementia, who find the experience of walking enjoyable (Dewing, 2006; Robinson *et al.*, 2007). This is an area which can cause particular concerns among family carers and care home staff. A systematic review supplemented by separate focus groups with practitioners, family carers, and people with dementia (Robinson *et al.*, 2007) concludes that this is an area in which everyone recognises the balance between rights and responsibilities. Family carers, people with dementia, and home care staff are more inclined to place the balance in favour of autonomy over safety, compared with professionals who are extremely conscious of negative reactions from the media and general public.

Rowe (2003, 34) emphasises the need to distinguish between *wandering* and *getting lost* in effective risk mitigation; 'people who wander may never become lost and those who never wander may become lost'. Analyses of instances where people with dementia have become lost highlight the need to alert emergency services as quickly as possible rather than wait and see if they return home (Rowe *et al.*, 2004).

Bearing in mind Rowe's distinction between walking and getting lost, the thoughtful use of support to enable people with dementia to travel to new places can help them achieve greater control over their lives:

> "We had a younger person with dementia attending our social group but what she really wanted to do was to go back to working in a shop. And there was our charity shop! We thought that she would be able to manage if we gave her some support as it was her anxiety that was really the problem. So a support worker went with her for the first three weeks and that has made all the difference to her confidence."
>
> Chief Executive, Voluntary organisation

Many people with dementia want to continue to travel outside their home. Support workers to accompany the person with dementia, helpcards, and assistive technology can all help people with dementia to go outside safely.

It can also be helpful to think about why a person with dementia wants to walk and move about, especially if he or she appears to be walking without a clear purpose in mind. The Alzheimer's Society factsheet (Alzheimer's Society, 2010d) considers some of the reasons for this behaviour and lists some ideas about approaches that family carers and care workers can take.

Other ideas about how to help mitigate the risks of walking include risk assessment screening tools (UK Wandering Network, 2005-2009) to identify those who are at greater risk of coming to harm if they leave home and helpcards (Alzheimer's Society, 2010b) that can be carried so that if a person with dementia becomes lost, other people will realise that he or she has dementia. Safe walking technologies (Robinson *et al.,* 2007; Doughty & Dunk, 2009), such as exit monitors and global positioning systems (GPS), indicate when people have left a building or monitor their movements while out. Identity bracelets or mobile telephones can also be used (Walker *et al.,* 2006; Robinson *et al.,* 2007), although it is important to remember that some people with dementia may see such devices as intrusive (Robinson *et al.,* 2007) and so they should not be used without discussion or consideration of the ethical issues.

This example from a family carer illustrates how getting lost is not the only potential area of concern when people with dementia are out walking:

> "When caring for my husband, he loved to walk and spent hours in our nearby park. The first two years I let him go alone because he could find his way there and I always knew where to find him. Without any evidence of change of behaviour or thinking and, given that I had accompanied him on dozens of occasions and emphasised that he must use the pedestrian crossing, I was horrified to spot him from a distance one day about to cross the road. Yes, he used the crossing but walked straight out into the road before cars had a chance to stop. A cyclist fell off his bike and was lucky the car next to him didn't swerve into him. I couldn't let my husband go out unaccompanied after witnessing this."
>
> (Family carer)

Living alone and being left alone

There is some evidence that, even when caring for someone with mild dementia, family carers do not like leaving people with dementia on their own (Walker *et al.,* 2006). This issue needs careful evaluation and is certainly a safety concern. These safety concerns also need to take on board the risks to family carers' health if they are providing care without any opportunities for a break. The US National Institute on Aging has produced

People with dementia living at home and their carers need support to reach decisions about leaving the person with dementia alone in the house.

the following checklist to help family carers decide what to do. The guide suggests that family carers may want to seek input and advice from a health care professional to assist them if any of these considerations apply and also advises that these questions need revisiting as dementia progresses:

Does the person with dementia:

- become confused or unpredictable under stress?

- recognise a dangerous situation, for example, fire?

- know how to use the telephone in an emergency?

- know how to get help?

- stay content within the home?

- wander and become disoriented?

- show signs of agitation, depression, or withdrawal when left alone for any period of time?

- attempt to pursue former interests or hobbies that might now warrant supervision, such as cooking, appliance repair, or woodworking?

(National Institute on Aging, 2009, 5)

It can be useful to review each room in the house in which the person with dementia lives separately to identify potential hazards.

Medication

There has been much discussion of the risks of medication for people with dementia – under- but also over-medication; and also the risks of people losing the ability to take their own medication:

> "Things gradually got worse so I took her [my mother] to GP who referred her to the memory clinic. The consultant…started her on Aricept and she did extremely well, and I thought it would be safe for her to go back to Trinidad. But when she was there she hid her medication apparently, and stopped taking it, so she deteriorated. I had to ask a neighbour to put her on a plane and send her back to London."
>
> (Marylynn, in: Whitman, 2010, 124-125)

Many family carers will have developed their own ways of prompting relatives to take their medication or may be assisting people directly. Where family carers are not involved, the risks of the person with dementia not taking medication or taking the wrong medication may cause particular problems. Dosset boxes, with separate compartments for the days of the week and times of day, are available from pharmacists and may be helpful to people with dementia living alone and also to care workers whose role involves assisting with medication.

An important area in which risk needs to be considered very carefully is in the use of anti-psychotic medication for people with dementia who have behavioural and psychological difficulties such as agitation, aggression, shouting, and sleep disturbance. Reviews (All Party Parliamentary Group on Dementia, 2009; Banerjee, 2009) suggest that the risks of harm from these drugs may outweigh the benefits, especially where prescriptions are not reviewed frequently enough (Alldred *et al.,* 2007).

Maximising risk and minimising restraint

Situations in which a person with dementia wants to go outside but which others consider are unsafe are an example of where ethical decisions about restraint may have to be made (Hughes & Baldwin, 2006). In some circumstances restraint is the right thing to do, and not to do so on these occasions could be considered neglect. Although designed for use in care homes, the materials recently produced by the Social Care Institute for Excellence (Owen & Meyer, 2009; Qureshi, 2009; Social Care Institute for Excellence, 2009a) on good practice in maximising risk and minimising restraint provide very helpful outlines of good practice and the legal context that can be used outside these settings. As this material from SCIE points out, in situations covering care home settings and hospitals staff will also need to be aware of the provisions of the Deprivation of Liberty Safeguards (DoLS) and should work under the Code of Practice (see Section on DoLS in the Legal Frameworks section). SCIE's website contains details of its Mental Capacity Act programme which is continually updated. It covers this subject as well as the Human Rights Act and the legal implications of maintaining dignity.

> *Resources exist to help care providers and family carers make decisions about when the risk of neglect is greater than the risk of restraining someone.*

In practice, Owen and Meyer (2009) recommend using a six-step framework to help make informed decisions in situations where the use of restraint is being considered. The six steps are:

• observe;

• do some detective work;

• consider the options;

• implement the plan;

• monitor; and

• review the plan.

They emphasise the need to avoid restraint by focusing care plans on what the person can do, by having clear policies involving residents, relatives and significant others in decision making, and by encouraging staff to reflect on their practice and receive training so that they can implement a culture of positive risk taking. They also point out that while 'restraint' is often seen in terms of practices such as locked doors, bedrails, and preventing a person from leaving, it can also apply to smoking, drinking alcohol, and sex. Many of the care home managers they spoke to had policies to ensure that positive risk taking was part of the culture of the home. This included recording whether the resident or family members were happy to accept the level of risk involved in certain activities or exploring whether alternative strategies could be developed that would lead to the same goal but with reduced levels of risk. Policies such as these can be especially helpful where differences of opinion exist within the same family.

Another way of helping care staff make decisions about where restraint may be necessary is the traffic light approach to care planning (Sells & Shirley, 2010). This is based on the idea that care plans may be constructed to address three different states.

- As the default setting, staff should be attending to the person's well-being (**green for go**).

- Staff need to be vigilant in a possible change in the person's mood (**amber for be prepared**).

- When an untoward event happens, it should be acted on immediately to maintain the safety of others (**red for stop**).

This approach aims to encourage staff to hold each of these states in mind as they are working with the person, and, most importantly, when the crisis is over, to work back through the sequence (red-amber-green) to support the person with dementia in meeting their daily needs.

Restraint can also happen in settings where the person with dementia lives on his or her own or with family members – for example, if a family carer locks the person with dementia in their house or flat while he or she goes shopping. In instances such as this, it is important to consider how the needs of family carers are considered alongside those of the person with dementia, for example, by providing a support worker or volunteer to visit the person while the family carer goes out. Carers' assessments (available from the local council adult services department) should consider the risks to family carers of not being able to take a break from caring.

Risk in communal settings

Some aspects of risk enablement are particularly, but not exclusively, associated with living in communal settings such as hospitals, care homes, and extra care housing.

Balancing the freedom of one individual against another

One feature that is more often encountered in communal settings is that one resident's right, or wish, to do something might be a risk to, or an infringement of, the rights or freedom of other residents. Owen and Meyer (2009) argue that care homes are communities where one resident's behaviour may both influence, and be influenced by, staff, visitors and other residents, meaning that staff face:

> *Staff working in communal settings face particular challenges in balancing the freedom of one individual while protecting the rights of another.*

…the key challenge of providing care in a communal setting where [they] are required to balance the freedom of one resident while protecting the rights of another.

(Owen & Meyer, 2009, 15)

There is little information about how this challenge applies in other communal settings, such as day care centres or dementia cafés, or other public spaces. A further issue in such settings is that people with dementia and family carers may be troubled by the risk of rejection or embarrassment, leading to the risk of social exclusion (Bruce, 2004).

Falls

Vulnerability to falls increases with age and with cognitive impairment (Vassallo *et al.,* 2009). Falls and the fear that patients or residents will fall can be a major concern in hospitals and care homes and can cause ethical dilemmas in terms of balancing autonomy and the perceived need to protect people with dementia from falling (Johansson *et al.,* 2009), although of course falls can also be a

> *Using risk assessment tools and taking practical steps to create a safer environment can help prevent falls in communal settings.*

problem among people living at home. Simple risk assessment tools such as the STRATIFY risk assessment tool (Oliver *et al.,* 1997) can help predict which people are at greater risk from falling (Oliver *et al.,* 2004). In communal settings, practical advice can include making sure bathing facilities and lavatories are well signposted, placing beds with adjustable heights on to the lowest position so that if a person falls they are at less risk of serious harm, placing bedside lockers on the side that the person prefers to get in and out of bed to re-enforce natural movement, and good communication between staff (Walker, 2004).

The risk of falls is also associated with taking a number of different types of medication (polypharmacy) and this is an independent risk factor for falls. People living in care homes are also thought to be at greater risk from the adverse effects of drug errors, partly because of the number of different medications they take and partly because of the ways in which the body reacts to drugs in old age (Barber *et al.,* 2009).

Monitoring change

An Australian study (Waugh, 2009) reports that interviewees identified a number of critical times in the lives of the persons with dementia that placed them at risk.

Risks change as dementia progresses. Positive risk taking helps people with dementia and their carers deal with each of these changes as they happen.

While recognising the uniqueness of every person with dementia with whom they worked, they felt that there were 'critical times' in his or life that posed especial risks. These were: at the time of diagnosis; if changes occurred in the person's behaviour; when there was a decline in their physical health; and as their social and life skills diminished resulting in increasing dependence or disability.

"Two weeks [before entering long term care], we had been cycling in Holland …I asked the consultant how it was possible to deteriorate this quickly. He said something really useful: that it's like walking on thin ice and the ice is getting thinner and thinner but you don't especially notice – until suddenly you fall through and your world is suddenly so different."

(Rachel, in Whitman, 2010, 49)

This final point makes risk enablement or positive risk taking particularly important. Some people with dementia may not have the time to wait for lengthy decisions about risk. While this type of sudden decline may be more associated with vascular dementia, which can have a step like progression, people with dementia may be at risk of other illnesses. There may only be the one opportunity for them to undertake a much missed familiar activity or to take the chance of trying something new. Family carers may value the support of practitioners to make the most of these possible windows or last chances. Such positive risk taking can be very positive in terms of building up trust and relationships between people with dementia, family carers, and practitioners.

Section C:
Risk enablement framework

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. Positive risk-taking is not negligent ignorance of the potential risks. Nobody, especially users or providers of a specific service or activity, will benefit from allowing risks to play out their course through to disaster. So, in practice it is usually a carefully thought-out strategy for managing a specific situation or set of circumstances.

(Morgan, 2004, 18)

What is this framework for?

Section A and B of *Nothing ventured, nothing gained* outline the key issues and evidence in considering risk with people with dementia. This Section – the *Nothing ventured, nothing gained framework* – provides a structure through which practitioners can assess, enable and manage risk with persons with dementia and their carers. The focus of the framework is on collaborative approaches that includes all relevant parties: people with dementia, their carer/s, family, friends, neighbours (where risk might impact upon them) and practitioners of all disciplines.

The framework has 4 steps:

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.

Organisations might want to adapt the framework to suit their own local circumstances and to add more detail.

Risk and people with dementia

A good quality of life, a good end of life, and good outcomes are essential for us all. Having dementia does not exempt a person from such aspirations. *Most people*

would agree that a life without risk would be rather unadventurous and dull. Risk is vital for positive feelings, experiences and achievements. Life with dementia can still be a life worth living. A good risk assessment should demonstrate that risk has been assessed and managed taking into account all perspectives and all aspects of the individuals needs. Practitioners should demonstrate that they have used all means available to skilfully communicate with the person with dementia to best understand their individual needs and wishes.

This risk framework guides practitioners to making good decisions with the person with dementia and their network of supporters and is based upon the dual necessities of individual empowerment and the promotion of safeguarding

The framework largely focuses on people with dementia who have problems making decisions or who are no longer able to do this, even with support. Anyone supporting a person who is not able to make a specific decision must abide by the Code of Practice of the *Mental Capacity Act 2005*. (See Legal Framework section for more information.) All practitioners must act in the person's best interests; their actions must be proportionate (not overreacting); and they must take the less restrictive alternative. This applies when supporting a person with dementia in a paid or unpaid role.

The framework may also be useful for people who are able to take their own decisions. It is a way of thinking about what might make a person vulnerable in certain situations and what can be done to help manage risks in a way that produces the results that people with dementia want.

Getting started: tips for best practice in assessing, enabling and managing risk

Practice tip: use biographical information

There are many ways in which biographical information can be obtained: talking to the person, using Talking Mats (Murphy *et al.,* 2007), observing their behaviour and reactions, talking to carers, family and friends and drawing on life story work. This will help to see which aspects of their life may be areas where positive risk taking can help.

Linda is a paid advocate and meets Doris on the hospital ward for the first time. Doris has severe dementia and little is known about her. She has no visitors and has very limited communication. Linda talks to her, but also contacts her GP service and her neighbours to try and build up a picture of Doris. She finds out that before she became ill Doris was a keen gardener. Linda uses this information when talking to the care team about the benefits of one care home over another; one has better facilities and on-site nursing and medical care, but the other has a garden that residents are able to go into easily although the home is not near healthcare services. Linda raises these points with the professionals when they are thinking about the risks of Doris going to the latter home.

Practice tip: abide by statements of wishes and advance care plans

Documents that may have been drawn up before a person loses the ability to make decisions may be useful resources. These might be 'statements of wishes' or 'advance care plans' or similar. Some people may have done work on Life Planning after they received the diagnosis of dementia, or before. This can be a useful guide to their wishes. People newly working with a person with dementia should make enquiries about any such documents. Similarly, people may have told others what they wish to happen to them in certain circumstances. This too is very useful, although a written document can give greater clarity. An increasing number of people have set up health and welfare elements of Lasting Powers of Attorney and the people they appointed should be involved in any discussions when this is activated.

Practice tip: engaging the right people in the process

If professionals and paid workers do not know the person well they might not be aware of the ways in which the individual already manages risk, or how their family or supporters have already built up systems of support. Here, it is important to have discussions with the individual and those closest to them and pay close attention to what they say. They may be managing some risks well and just need support to exercise this power. In other areas, they may appreciate specialist knowledge and experience. There is evidence that people with dementia and their family carers welcome information and advice, especially when it is tailored to the individual and sensitive to current worries.

Example: planning for risk together

David is looking after his wife Emily, who has severe dementia, at home but he needs to go to hospital for an operation. He talks with the manager of the care agency about his routine so that the care workers who will look after Emily when he is away are not worried about some of Emily's actions. He thinks it is important to maintain her routine as much as possible. This means she gets less distressed. For example, Emily is not able to make her own decisions about managing money so David gives her photocopied bank notes so that she feels she still has money in her purse. He tells the care agency about this in case their workers worry about Emily giving them money when he is not there. David also plans for the risk that he will be in hospital longer than he expects and in the event that things go wrong.

Practice tip: understanding mental capacity frameworks

It is important that we have also taken into account our own feelings about a person's ability to make decisions for themselves. The *Mental Capacity Act 2005* principles state that it should be assumed that people with dementia do have the capacity to make their own decisions unless it is established that they do not. Any decisions made on a person's behalf must be in their best interests rather than based on the assumptions, needs or wants of others. In essence, an activity or an arrangement should be permitted or respected unless risk analysis, including an assessment of capacity if this is in doubt and determination of best interests, shows it should not.

Practice tip: understand your own fears

Some people find it helpful to think about their own fears in relation to the activity and therefore their own perceptions of risk. Our own feelings can be compared with those of the person and sometimes their carers or supporters. Professionals try to arrive at an objective and balanced position so that people may take sensible decisions about risks or when acting in their best interests. This is often best achieved by gaining opinions from a range of people close to the person as well as from the person themselves about the risks, and coming to an agreed, shared view about risk in partnership with the individual, their supporters and professionals. It may take time and skill but the outcome will be that risk empowerment is less dominated by fear and overestimates of danger.

Step 1: Start with the person's hopes, needs and aspirations

A person-centred framework to risk starts with understanding what is important to the person with dementia. Wellbeing is promoted by meeting psychological needs for love, comfort, identity, occupation, inclusion and attachment, or having them met for us (Kitwood, 1997; Baldwin & Capstick, 2007).

Different individuals have varying degrees of each of these needs. A good starting point for considering risk can be thinking about how much a particular activity is likely to contribute to – or take away from – the quality of life for the person with dementia. This must then be balanced with the degree to which the activities that will satisfy these needs 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.

Thinking about what people need in order to maximise their quality of life provides the context within which people who have the power or authority to make decisions can balance positive risks against danger or likelihood of harm. Lowering or eliminating the risks of activities or arrangements that are important to people may reduce some risk but at the potential expense of their happiness and fulfilment. They may also affect chances of re-enablement or rehabilitation, such as regaining abilities to walk or to go to the toilet independently.

The table below provides a framework for outlining an individual's psychological and social needs. The purpose of this ranking is not to choose one need over another. Rather, it assists in understanding what is important from the person's perspective. Use the middle column to rank a person's needs from 1 (most important to them) to 7 (least important to them), as a way of working out what quality of life means for them. If you don't want to use numbers, you could use descriptive words such as 'very', 'quite', 'not very' as a way of differentiating between different aspects of people's lives.

Insert in the right column biographical or personal information about how the respective need domain is satisfied.

Understanding the person's psychological and social needs

Psychological and social needs	Order 1-7	How I like these needs to be met
Love: Feeling unconditionally accepted		
It was really hard when the doctor told me and my daughter Elaine that I had dementia. I wondered how I was going to tell everyone and what they would think of me	1	Elaine and I got the booklet 'The Milk's in the Oven' (Mental Health Foundation, 2005) for my grandchildren'. I have told people I know well that it's dementia but I still prefer to talk about memory problems. It's been hard with Elaine because our roles seem to be reversed but it's getting better

Psychological and social needs	Order 1-7	How I like these needs to be met
Comfort: Feelings of closeness to others		
Every Wednesday evening Elaine comes round after work. I make the tea, pour it out, and we put our feet up and talk about what's happening in the family	2	I like to make the tea myself – no-one can make it just the way I like it. I'm trying to remember not to overfill the kettle so it's lighter and easier to manage. It's more ecological too
Identity: Knowing your story and who you are		
I really enjoyed my job in the local department store. I still like going to see what they have in the shop. I make sure that I have got some cash with me in case I see anything I fancy. Mostly I just do window shopping though.	6	I only take out £20 at a time. I've got a chip and signature card for anything more expensive. I've agreed to let Elaine check my bank statements. I don't like it but it's better than not being able to keep control of my money.
Occupation: activities with personal significance		
I love dancing – my husband Jack and I used to go ballroom dancing. I wish I could go somewhere where I could have a good old dance.	5	My grandson Jason has found me the address of an old time dance club. I'm going to use my direct payment to see if I can find a support worker to take me dancing and make sure I have a dancing partner.
Inclusion: having a distinct place in a group		
I felt very lonely when I first went to the day centre. Everyone seemed to know each other. I was glad when my key worker Anne introduced me to everyone when she came back from holiday and I realised that two of my old neighbours went to the centre too.	4	I like to be properly introduced to everyone. In Anne's group, we all brought along a photograph of ourselves and wrote our name on it along with something we like. Anne got them copied so we each know each other's name and a bit about everyone else.

Psychological and social needs	Order 1-7	How I like these needs to be met
Attachment: specific emotional bonds with people (including pets or place/objects)		
I keep the window open at the back because the cat from next door likes to come in for a visit	7	If I got a cat flap, I wouldn't need to keep the window open. It's a bit strange having a cat flap and not owning a cat but I won't need to keep on trying to remember if the window's open or not.
Environment: sense of safety and security		
I got lost last week when I went into town. Fancy that, I've lived here for over 40 years! Luckily I met my neighbour but he said he doesn't normally come home that way. I'll have to think what I can do so it doesn't happen again.	6	I've got a helpcard which lets people know about my memory problems and Elaine has got me a mobile phone. Her number is stored on it and the number of a reliable mini cab firm. She's put her mobile number on speed dial – I just need to remember she's number one!

Step 2: Identifying key risks for the person with dementia and others

Most activities carry with them some level of risk, but often contain some value to an individual. The challenge is to ensure that an assessment of the risk takes account of the value of the activity to the person. Research shows that for people with dementia there are times when some risks increase or decision making may be harder or more complicated. These are times or events when the individual or those supporting them, paid or unpaid, should review the situation. These will differ between individuals but may be:

1. At the time of diagnosis of the dementia or realisation of what it means – this may be a very emotionally disruptive time and so behaviour and thinking (and therefore risk judgments) may be different from usual. People may be able to make decisions but it may be advisable to wait awhile if possible.

2. When there are changes in behaviour – this can arise from change in the nature of the condition or another health problem, or a change in support (different routine or care worker) or accommodation (moving to a care home, for example, or in with a relative), and therefore a re-assessment of risks might be helpful.

3. When there is a decline in physical or mental health – again, this might lead to a change in ability and new risks may emerge.

4. When there are increasing levels of disability – alongside possible problems with life and social skills, again prompting a change in the person's ability to manage risks. Loss of hearing may affect people's abilities to manage some risks, for example, or loss of sight.

Family carers and all those involved in supporting a person with dementia may want to bear in mind the need to consider such changes when considering risks, and the extent to which changes may increase a person's distress. For example, greater uncertainty or anxiety about their condition or routine may increase the need for support or comfort from others to provide emotional security – but this might also suggest that new or different social activities could be welcome.

The key risk areas that should be considered when weighing up your approach to managing the risk attached to a particular activity or arrangement are outlined below.

Readers might like to try this with a few examples, such as considering a person's access to tools (possible injury but enjoyment), a person's access to matches (fire hazard but control over their environment in lighting the living room fire), a person's wish to travel alone by train (possibly getting lost but independence and enjoyment), a person's wish to collect their pension in cash or get their money from a 'hole in the wall' (ATM) (chance of theft or loss but also pride and a sign of normality).

This scoring system helps to identify ways of reducing either the **likelihood** of something bad happening or the **severity** of the harm/danger. As with many other risk assessments, using an agreed measure (high H, medium M and low L) can be helpful in sharing and challenging perceptions about the level of risk.

Identifying risks and impacts

Risk area	What would be the impact if harm happened?	How likely (H/M/L)		How severe (H/M/L)	
		Myself	Others	Myself	Others
Physical risk	Example: access to tools leads to bruise from hammer – very minor injury, slight pain				

Risk area	What would be the impact if harm happened?	How likely (H/M/L)		How severe (H/M/L)	
		Myself	Others	Myself	Others
New activity/ break of routine	Example: dancing leads to tiredness and dizzy spell				
Doing something alone	Example: goes to Post Office – gets lost on the way and cold				
New relationships	Example: invites new 'friend' home – leads to exploitation				
Financial loss or loss of belongings	Example: pays someone to clean windows but not done – conned/exploited				

Step 3: assessing the impact of risk

It might be helpful to think about each of the 'risks' identified above using the examples as a guide but also thinking about other types of risk and in so doing reach agreement about the best way to mitigate them. Risks should be thought about for the whole person and the extent to which all of them are promoting quality of life.

The personal risk portfolio or 'heat map' below provides a framework in which to consider each 'risk' (behaviour or activity) as a balance between quality of life and risk. Here there is no scoring system. Rather, it can be used to trigger a meaningful discussion between the key parties involved. If necessary, you might want to add a column that considers risk to others. For example, where a person lives in a block of flats, wants to continue to use a cooker, but where there is a risk of leaving pans to burn. The heat map can be used either to chart a number of risks or to explore a single issue in depth.

As a result of this analysis, a strategy for mitigating risks and plotting them on the 'heat' map can be worked out. Such a map might be useful in talking about risk empowerment with a range of professionals or supporters, as well as the person with dementia if this is possible, and any carer. Some people with dementia may have an advocate and this person should be included.

People with responsibilities for the care of a person who is unable to make the decisions themselves may find that this approach can form the basis of a plan, to work out what is going to be done to safeguard the person and ensure they have

the opportunity to benefit from the activities or the arrangements in question. This plan can be written down or recorded and shared with other people supporting the person with dementia.

Personal Risk Portfolio ('heat map')

Contribution to
quality
of life

	High	Medium	Low
High	<u>Maximise</u> safety enhancement and risk management protect the individual <u>and</u> manage the activity	<u>Carefully balance</u> safety enhancement and activity management to protect the person	Minimal safety enhancement necessary – carry out with normal levels of safety enhancement
Medium	Substitute can the same personal benefit be delivered in a different way seek different activities?	<u>Carefully balance</u> safety enhancement and activity management to protect the person	Minimal safety enhancement necessary – carry out with normal levels of safety enhancement
Low	Do not allow 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	Allow the activity or seek alternatives that will provide a better relationship with their needs

High   Medium   Low

Risk of harm or quality of life to the individual

Step 4: Risk enablement, management and planning

The primary need for people supporting people with dementia is to identify the ways in which the person with dementia can maximise their quality of life and do the things they wish to do without being placed in undue danger or suffering harm, or harming other people. It is helpful to think about ways in which risks can be managed for people who cannot make their own decisions in the following order:

1. Enablement – can we promote the person's safety without interfering with their enjoyment of an activity? If this is sufficient to make the risk acceptable, there is no need to change the way that the activity is carried out. Examples of this might be taking part in sport or socializing. But if, for instance, a care home resident keeps walking in to the bedrooms of other residents and causing them distress then a strategy needs to be put in place that meets everyone's needs as far as possible.

> Example: Marianne loves dancing to music – her home care worker moves the furniture aside and they dance together in the sitting room, making sure there is a sofa for them to collapse on when tired out.

Assistive technologies/equipment might be well placed to reduce the negative impact on the person if harm occurs or a problem arises. For instance, there are ways in which people can be given support in the event that they become lost, if they forget where they put keys, or if they tend to leave household appliances, like the cooker, on. This does not necessarily seek to reduce the risk, rather to protect the person, or others, in the event of the risk becoming realised.

2. Management – are there ways in which we can change the way that a person with dementia takes part in an activity or makes an arrangement to reduce the risk to acceptable levels whilst still respecting their choices and promoting their quality of life? Examples here might come from efforts supporting a person to live at home or in employing a support worker. At its most serious, where restraint or Deprivation of Liberty (DoLS) is concerned, there is guidance on the processes that must be considered in the DoLS Code of Practice.

New approaches to risk management are more likely to be about the activity itself, and seek either to reduce the likelihood of the risk of harm occurring or to reduce its impact, if it does occur. This provides scope for thinking about changing what the activity or arrangement involves; where it takes place; how it happens; or finding alternative ways of meeting the person's choices and wishes. Living alone may seem risky, for example, but it may be what people have said they want to do as long as possible.

> Example: Saleema wants to employ a care worker to look after her husband Adil when she is at work. She has advertised for a male care worker, ideally who shares Adil's interests in sport. They interview applicants with a friend who is a local businessman. They choose the person who Adil seems to react well to and make sure that they take up references in person, asking the person they wish to employ if they are willing to undertake a Criminal Record Bureau check, which they will pay for.

The real goal is to enable the person to be where they want and to do what they choose, so that this will enhance their quality of life, but without undue risk of harm to themselves or others and in line with the legal framework respecting human rights.

> "If risk and quality of life had been viewed positively, my dad would have remained independent for far longer than he did. It was due to pressure from professionals with regard to his safety that my brother and I were persuaded that he should be moved to a care home – a dreadful place for him."
>
> (Family carer)

Many of the risks to a person with dementia who has limited capacity or is not able to make decisions (see *Mental Capacity Act 2005* and its *Code of Practice*) may be brought together to gain a picture of opportunities and risks. This helps to consider different risks being faced – it is important that people don't think about this as seeking to minimise overall risk. Rather people with dementia and their supporters seem to want balances in the risks being taken, with enough risk being taken to satisfy the person's wishes and needs, but with risks being managed in terms of safeguarding the person.

The final step in assessing risk is to bring together the findings from steps 1, 2 and 3 into a care plan. The care plan will summarise the risk assessment, enablement solutions and the actions that are necessary to manage residual risk.

The table below on risks, safety enhancements, harm reductions, resources and responsibilities offers an example of how the processes of risk assessment, enablement and management have been developed from the viewpoint of different people with dementia. It is advisable to hold regular reviews of the risk enablement and risk management process but the frequency of those reviews will vary according to individual circumstances.

The goal is to manage risks in ways which improve the quality of life of the person, to promote their independence, or to stop these deteriorating if possible. Not all risks can be managed or mitigated, but some can be predicted.

Risks, safety enhancements, harm reductions, resources and responsibilities

I value this activity*	The risks associated with this activity are...	How I can enhance my quality of life	How I will manage the risk
Playing golf is a key part of my retirement. I enjoy socialising, being outside in the fresh air and the exercise	*I am at risk of getting hurt by wandering in 'line of fire'. I get very tired which leads to feeling distressed*	My friend, Fred, has a good understanding of my current needs and I will only play golf when Fred is around. My wife or the CPN will provide Fred with the information he needs to continue to accompany me on the golf course. Fred and I will play golf for a short period of time and take a rest in the club house	I will not play golf if Fred is not available to come with me
I enjoy cooking. I've cooked all my life for my family and it's important to me to continue to look after myself	*I've left the cooker on a couple of times and burnt a pan. There's a risk that a fire will start and cause harm to me and my neighbours*	A gas shut off valve will be fitted to the cooker and an extreme heat sensor will be fitted in the kitchen	If further problems occur with cooking I will talk with my care manager about alternative options such as using a microwave, arranging for someone to cook with me, or having meals delivered

I value this activity*	The risks associated with this activity are…	How I can enhance my quality of life	How I will manage the risk
I get out of bed at night and go out for a walk because I don't realize the time of time. My neighbours say I've been knocking on their doors and waking them up. I really want to stay in my own home.	*I am at risk of attack if I go out into the street during the night. My neighbours are already being woken by my walking and this is having a serious impact on them*	I have already put a clock by the front door and a sign that reminds me to check if it's night time.	I've had a 'Just Checking' assessment and it shows I'm inactive much of the day – probably dozing in the chair – and then active at night time. I'm going to try to stay awake all day and avoid napping in the afternoon so that I am tired at night time. I've got a programme of daytime activities to keep me occupied, my care worker will call round or phone me to see if I'm awake after lunch when I've been dozing off. In the evening, my daughter will call me to tell me it's time to go to bed.

*See table on 'Understanding psychological needs and social needs.

Closing thoughts

This guidance has brought together a range of experience and expertise. There is wide support for changing the emphases of dementia care to risk enablement. The *National Dementia Strategy* and the new outcomes implementation framework (Department of Health, 2010) provides a springboard for this change. It is clear that there is much goodwill to make it a reality and to leave a legacy of

commitment to risk enablement. At a time when there is also great concern to get safeguarding right – not least for people with dementia – it is important to build on accounts of what works well and not so well in mitigating risks. Practitioners do not have all the answers but there seems to be widespread acceptance that they have some expertise and that there are now more checks and balances in risk enablement. Above all, this review suggests that it is important not to close down options prematurely; that we should be looking for creative solutions, that we need to realise that others are facing similar challenges, that we may find the process of seeking advice and support is, in itself, helpful. There is a groundswell of support for seizing opportunities to considering quality of life gains as well as potential harm, and this needs to be backed by support for making the most of the decision making capacities that the person with dementia often retains. And, where this is lost, there still needs to be respect for the individual and family regardless of a person with dementia's ability to make decisions.

Acknowledgements

U Hla Htay, family carer

Steve Iliffe, University College London

Steve Jamieson, Royal College of Nursing

Des Kelly, National Care Forum

Maggie Kirby-Barr, Member of Social Care Workforce Research Unit Service User and Carer Advisory Group

Deborah Klee, social and healthcare consultant

Tina Lightfoot, Essex County Council

Shamime Lakdawala, Family carer

Drew Lindon, Homeless Link and formerly of The Princess Royal Trust for Carers

Karen Lowton, Institute of Gerontology, King's College London

Michael Mandelstam, Independent consultant and trainer

Neil Mapes, Consultant to Mental Health Foundation

Paul Marks, HM Deputy Coroner, West Yorkshire (Western District)

Alisoun Milne, University of Kent

Veronica Monks, Department of Health

Esme Moniz-Cook, Hull Memory Clinic

Ann Netten, University of Kent

Clive Newton, Age UK

Shirley Nurock, Family carer and researcher

Martin Orrell, University College London

Tom Owen, My Home Life

Mike Padgham, United Kingdom Home Care Association

Andrew Papadopoulos, Birmingham & Solihull Mental Health NHS Foundation Trust

Kathryn Parson, Older People's Advocacy Alliance

Bridget Penhale, University of East Anglia

Liz Price, University of Hull

Leo Quigley, Department of Health

Joan Rapaport, Social Care Workforce Research Unit, King's College London

Kritika Samsi, Social Care Workforce Research Unit, King's College London

Louisa Shirley, Northumberland Tyne & Wear Foundation Trust

Bernadette Simpson, Department of Health

Graham Stokes, BUPA

Patricia Suarez, NHS Confederation

Brian Taylor, University of Ulster

Jeanette Thompson, Sheffield City Council

Daphne Wallace, retired old age psychiatrist and person with dementia

Dawn Warwick, London Borough of Wandsworth

Simon Williams, Association of Directors of Social Services and London Borough of Merton

Toby Williamson, Mental Health Foundation

References

Adams, T. (2001) 'The social construction of risk by community psychiatric nurses and family carers for people with dementia', *Health, Risk & Society*, 3(3): 307-319.

Age Concern (2008) *Out of Sight, Out of Mind: social exclusion behind closed doors*, London: Age Concern England.http://www.ageconcern.org.uk/ AgeConcern/Documents/Out_of_sight_out_of_mind_Feb08.pd.

Aggarwal, N., Vass, A.A., Minardi, H.A., Ward, R., Garfield, C. & Cybyk, B. (2003) 'People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care', *Journal of Psychiatric & Mental Health Nursing*, 10(2): 187-197.

Alaszewski, A. (1998a) 'Health and welfare: managing risk in late modern society', in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds), *Risk, Health and Welfare*, 127-153, Buckingham: Open University Press.

Alaszewski, A. (1998b) 'Risk in the modern society', in Alaszewski, A., Harrison, L. and Manthorpe, J. (eds), *Risk, Health and Welfare*, 1-23, Buckingham: Open University Press.

Alaszewski, A., Alaszewski, H., Manthorpe, J. & Ayer, S. (1998) *Assessing and Managing Risk in Nursing Education and Practice: supporting vulnerable people in the community*, London: English National Board for Nursing, Midwifery and Health Visiting. Retrieved 29 July 2010 from.

All Party Parliamentary Group on Dementia (2009) *Always a Last Resort: inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes*, London: Alzheimer's Society. Retrieved 21 July 2010 from http://www. alzheimers.org.uk/site/scripts/download_info.php?fileID=322.

Alldred, D.P., Petty, D.R., Bowie, P., Zermansky, A.G. & Raynor, D.K. (2007) 'Antipsychotic prescribing patterns in care homes and relationship with dementia', *Psychiatric Bulletin*, 31(9): 329-332.

Alzheimer's Society (2008a) *Adaptations, improvements and repairs to the home*. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/428.

Alzheimer's Society (2008b) *Assistive technology*. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/437.

Alzheimer's Society (2008c) *Driving and dementia*. Retrieved 29 July 2010 from http://alzheimers.org.uk/factsheet/439.

Alzheimer's Society (2008d) *Maintaining everyday skills*, London: Alzheimer's Society. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/521.

Alzheimer's Society (2008e) *Safety in the home*. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/503.

Alzheimer's Society (2009) *Financial and legal affairs*. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/467.

Alzheimer's Society (2010a) *Factsheets*. Retrieved 1 March 2010 from http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200137.

Alzheimer's Society (2010b) *Helpcards for people with dementia*. Retrieved from http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200192&documentID=360

Alzheimer's Society (2010c) *The later stages of dementia*. Retrieved 29 July 2010 from http://alzheimers.org.uk/factsheet/439.

Alzheimer's Society (2010d) *Moving and walking about*. Retrieved 29 July 2010 from http://www.alzheimers.org.uk/factsheet/501.

Alzheimer Europe (2009) *Driving: dealing with practical issues*. Retrieved 25 February 2010 from http://www.alzheimer-europe.org/Living-with-dementia/Having-dementia/Dealing-with-practical-issues/Driving.

Alzheimer Scotland – Action on Dementia (Undated) *Don't Make the Journey Alone*, Edinburgh: Alzheimer Scotland – Action on Dementia. Retrieved 1 March 2010 from http://www.alzscot.org/downloads/dontmake.pdf.

Aminzadeh, F., Byszewski, A., Molnar, F.J. & Eisner, M. (2007) 'Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives', *Aging & Mental Health*, 11 281-290.

Association of Directors of Adult Social Services/Department of Health (2009) *National Dementia Strategy. Objective 6 – improved community personal support: Think Tank report*, London: Association of Directors of Adult Social Services/ Department of Health. Retrieved 29 July 2010 from.

at dementia (Undated) *About assistive technology*. Retrieved 29 July 2010 from http://www.atdementia.org.uk/listChildren.asp?page_id=17.

Baldwin, C. (2005) 'Narrative, ethics and people with severe mental illness', *Australian and New Zealand Journal of Psychiatry*, 39(11-12): 1022-1029.

Baldwin, C. (2008) 'Narrative(,) citizenship and dementia: the personal and the political', *Journal of Aging Studies*, 22(3): 222-228.

Baldwin, C. & Capstick, A. (eds) (2007) *Tom Kitwood on Dementia: a reader and critical commentary*, Maidenhead: Open University Press.

Banerjee, S. (2009) *The Use of Antipsychotic Medication for People with Dementia: time for action*, London: Department of Health. Retrieved 29 July 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf.

Barber, N.D., Alldred, D.P., Raynor, D.K., Dickinson, R., Garfield, S., Jesson, B., Lim, R., Savage, I., Standage, C., Buckle, P., Carpenter, J., Franklin, B., Woloshynowych, M. & Zermansky, A.G. (2009) 'Care homes' use of medicines study: prevalence, causes and potential harm of medication errors in care homes for older people', *Quality and Safety in Health Care*, 18(5): 341-346.

Bartlett, R. (2007) ''You can get in alright but you cant get out'. Social exclusion and men with dementia in nursing homes: insights from a single case study', *Quality in Ageing*, 8(2): 16-26.

Births and Deaths Registration Act 1953. Retrieved 29 July 2010 from http://www.opsi.gov.uk/RevisedStatutes/Acts/ukpga/1953/cukpga_19530020_en_1.

Bond, J., Corner, L., Lilley, A. & Ellwood, C. (2002) 'Medicalization of insight and caregivers' responses to risk in dementia', *Dementia*, 1(3): 313-328.

Bornat, J. & Bytheway, B. (2010) 'Perceptions and presentations of living with everyday risk in later life', *British Journal of Social Work*, 40(4): 1118-1134.

Bowie, S. (2009) *Chalk and cheese*, Dementia Awareness Week Conference 2009: Let's get personal – personalisation and dementia, Edinburgh: Alzheimer Scotland – Action on Dementia. Retrieved 29 July 2010 from http://www.alzscot.org/pages/dementia-awareness-week-conference-presentations.htm.

Breen, D.A., Breen, D.P., Moore, J.W., Breen, P.A. & O'Neill, D. (2007) 'Driving and dementia', *British Medical Journal*, 334(7608): 1365-1369.

Bruce, E. (2004) 'Social exclusion (and inclusion) in care homes', in Innes, A., Archibald, C. and Murphy, C. (eds), *Dementia and Social Exclusion*, 123-136, London: Jessica Kingsley Publishers.

Buri, H. & Dawson, P. (2000) 'Caring for a relative with dementia: a theoretical model of coping with fall risk', *Health, Risk & Society*, 2(3): 283-293.

Carpenter, B.D., Xiong, C., Porensky, E.K., Lee, M.M., Brown, P.J., Coats, M., Johnson, D. & Morris, J.C. (2008) 'Reaction to a dementia diagnosis in individuals with Alzheimer's Disease and mild cognitive impairment', *Journal of the American Geriatrics Society*, 56(3): 405-412.

Carr, S. (2010) *Enabling risk, ensuring safety: self-directed support and personal budgets*, London, Social Care Institute for Excellence.

Carr, S. & Robbins, D. (2009) *The implementation of individual budget schemes in adult social care*, London: Social Care Institute for Excellence. Retrieved 29 July 2010 from http://www.scie.org.uk/publications/briefings/files/briefing20.pdf.

Cheston, R., Jones, K. & Gilliard, J. (2003) 'Group psychotherapy and people with dementia', *Aging & Mental Health*, 7(6): 452-461.

Clarke, C.L. (1995) 'Care of elderly people suffering from dementia and their co-resident informal carers', in Heyman, B. (ed), *Researching User Perspectives on Community Health Care*, 135-149, London: Chapman and Hall.

Clarke, C.L. (2000) 'Risk: constructing care and care environments in dementia', *Health, Risk & Society*, 2(1): 83-93.

Clarke, C.L., Gibb, C.E., Keady, J., Luce, A., Wilkinson, H., Williams, L. & Cook, A. (2009) 'Risk management dilemmas in dementia care: an organizational survey in three UK countries', *International Journal of Older People Nursing*, 4: 89-96.

Clarke, C.L., Keady, J., Wilkinson, H., Gibb, C.E., Luce, A., Cook, A. & Williams, L. (2010) 'Dementia and risk: contested territories of everyday life', *Journal of Nursing & Healthcare of Chronic Illness*, 2(2): 102-112.

Cole-King, A. & Leppina, P. (2010) 'will the UK government change our approach to risk?', *British Medical Journal*, 341(7765): 204.

Dawson, J.D., Anderson, S.W., Uc, E.Y., Dastrup, E. & Rizzo, M. (2009) 'Predictors of driving safety in early Alzheimer disease', *Neurology*, 72(6): 521-527.

De Witt, L., Ploeg, J. & Black, M. (2009) 'Living on the threshold: the spatial experience of living alone with dementia', *Dementia*, 8(2): 263-291.

Dementia Services Development Centre (2007) *Best Practice in Design for People with Dementia*, Stirling: Dementia Services Development Centre.

Department of Health (2007) *Independence, choice and risk: a guide to best practice in supported decision making*, London: Department of Health. Retrieved 29 July 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074775.pdf.

Department of Health (2009) *Living Well with Dementia: a national dementia strategy*, London: Department of Health. Retrieved 27 October 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf.

Department of Health (2010) *Quality Outcomes for People with Dementia: building on the work of the National Dementia Strategy*, London: Department of Health. Retrieved 27 October 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf.

Department of Health/Department for Children, Schools and Families, (2009) *Guidance on Direct Payments for Community Care, Services for Carers and Children's Services,* London: Department of Health. Retrieved 29 July 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_104895.pdf.

Department of Health/Welsh Assembly Government (2007) *Mental Capacity Act 2005: Residential Accommodation Training Set*, London: Department of Health. Retrieved 29 July 2010 from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074618.pdf.

Dewing, J. (2006) 'Wandering into the future: reconceptualizing wandering 'A natural and good thing", *International Journal of Older People Nursing*, 1(4): 239-249.

Doughty, K. & Dunk, B. (2009) 'Safe walking technologies for people with mild to moderate cognitive impairments', *Journal of Assistive Technologies*, 3(2): 54-59.

Draper, B., Peisah, C., Snowdon, J. & Brodaty, H. (2010) 'Early dementia diagnosis and the risk of suicide and euthanasia', *Alzheimer's and Dementia*, 6(1): 75-82.

Elias, M.F., Beiser, A., Wolf, P.A., Au, R., White, R.F. & D'Agostino, R.B. (2000) 'The preclinical phase of Alzheimer Disease: a 22-year prospective study of the Framingham Cohort', *Archives of Neurology*, 57(6): 808-813.

Erlangsen, A., Zarit, S.H. & Conwell, Y. (2008) 'Hospital-diagnosed dementia and suicide: a longitudinal study using prospective, nationwide register data', *American Journal of Geriatric Psychiatry*, 16(3): 220-228.

Gateshead Council (2009) *Gateshead Positive Risk taking policy*, Gateshead: Gateshead Council. Retrieved 25 February 2010 from http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/Risk/?parent=3151&child=5008.

Gilmour, H., Gibson, F. & Campbell, J. (2003) 'Living alone with dementia: a case study approach to understanding risk', *Dementia*, 2(3): 403-420.

Glendinning, C., Challis, D., Fernández, J.-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: final report*, York: Social Policy Research Unit. Retrieved 13 May 2010 from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505.

Green, D. (2008) 'Risk and social work practice', *Australian Social Work*, 14(3): 154-156.

Harris, P.B. (2006) 'The experience of living alone with early stage Alzheimer's Disease: what are the person's concerns?', *Alzheimer's Care Quarterly*, 7(2): 84-94.

Health and Safety Executive (Undated) *ALARP "at a glance"*. Retrieved 1 March 2010 from http://www.hse.gov.uk/risk/theory/alarpglance.htm.

Huby, G., Brook, J.H., Thompson, A. & Tierney, A. (2007) 'Capturing the concealed: Interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalization', *Journal of Interprofessional Care*, 21(1): 55-67.

Hughes, J. & Baldwin, C. (2006) *Ethical Issues in Dementia Care: making difficult decisions*, London: Jessica Kingsley Publishers.

Hughes, J.C., Hope, T., Reader, S. & Rice, D. (2002) 'Dementia and ethics: the views of informal carers', *Journal of the Royal Society of Medicine*, 95(5): 242-246.

Iliffe, S. & Manthorpe, J. (2004) 'Editorial: the hazards of early recognition of dementia: a risk assessment', *Aging & Mental Health*, 8(2): 99-105.

Innes, A., Archibald, C. & Murphy, C. (eds) (2004) *Dementia and Social Exclusion*, London: Jessica Kingsley Publishers.

Johansson, I., Bachrach-Lindstrom, M., Struksnes, S. & Hedelin, B. (2009) 'Balancing integrity vs risk of falling – nurses' experiences of caring for elderly people with dementia in nursing homes', *Journal of Research in Nursing*, 14(1): 61-73.

Kemshall, H. (2009) *Defensible Decisions for the OLR*. Retrieved 28 July 2010 from http://www.rmascotland.gov.uk/try/rma-publications-and-presentations/presentations.

Kemshall, H. (2010) 'Risk rationalities in contemporary social work policy and practice', *British Journal of Social Work*, 40(4): 1247-1262.

Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*, Buckingham: Open University Press.

Lecouturier, J., Bamford, C., Hughes, J., Francis, J., Foy, R., Johnston, M. & Eccles, M. (2008) 'Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice", *BMC Health Services Research*, 8(1): 95. Retrieved 29 July 2010 from http://www.biomedcentral.com/1472-6963/8/95.

Life Story Network (Undated) *The National Lifestory Network* Retrieved 23 August 2010 from http://www.lifestorynetwork.org.uk/.

London Borough of Newham (2009) *LBN Risk enablement panel*, London: London Borough of Newham. Retrieved 29 July 2010 from http://www.dhcarenetworks. org.uk/Personalisation/Topics/Browse/Risk/?parent=3151&child=5007.

Lu, Y.-F., Yvonne, Haase, J.E. & Farran, C.J. (2007) 'Perspectives of persons with mild cognitive impairment: sense of being able', *Alzheimer's Care Quarterly*, 8(1): 75-86.

Manthorpe, J. (2004) 'Risk taking', in Innes, A., Archibald, C. and Murphy, C. (eds), *Dementia and Social Exclusion*, 137-150, London: Jessica Kingsley Publishers.

Manthorpe, J. (2009) 'Decisions, decisions...linking personalization to person-centred care', in O'Connor, D. and Purves, B. (eds), *Decision-making, Personhood and Dementia: exploring the interface*, 91-105, London: Jessica Kingsley Publishers.

Manthorpe, J., Samsi, K. & Rapaport, J. (In press) Changing practice: social workers' accounts of working within the Mental Capacity Act 2005.

Martin, S., Kelly, G., Kernohan, W.G., McCreight, B. & Nugent, C. (2008) 'Smart home technologies for health and social care support', *Cochrane Database of Systematic Reviews 2008*(4): Article number: CD006412. Retrieved 29 July 2010 from http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/ CD006412/frame.html.

McDermott, S. (2010) 'Professional judgements of risk and capacity in situations of self-neglect among older people', *Ageing & Society*, 30(6): 1055-1072.

McKeown, M., Hinks, M., Stowell-Smith, M., Mercer, D. & Forster, J. (1999) 'Q methodology, risk training and quality management', *International Journal of Health Care Quality Assurance*, 12(6): 254-266.

Mendez, M.F., Lauterbach, E.C., Sampson, S.M. & ANPA Committee on Research (2008) 'An evidence-based review of the psychopathology of frontotemporal dementia: a report of the ANPA Committee on Research', *Journal of Neuropsychiatry and Clinical Neurosciences*, 20(2): 130-149.

Mental Capacity Act 2005. Retrieved 29 July 2010 from http://www.opsi.gov.uk/ acts/en2005/2005en09.htm.

Mental Health Foundation (2005) *The Milk's in the Oven*, London: Mental Health Foundation. Retrieved 23 August 2010 from http://www.mentalhealth.org.uk/ publications/?char=M.

Mental Health Foundation (Undated) *Dementia Choices*. Retrieved 1 March 2010 from http://www.mentalhealth.org.uk/our-work/older-people/dementia-choices/.

Milne, A. (2010) 'Dementia screening and early diagnosis: the case for and against', *Health, Risk & Society*, 12(1): 65-76.

Ministry of Justice (2008) Mental Capacity Act 2005: *Deprivation of liberty safeguards – Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice*, London: Ministry of Justice. Retrieved 29 July 2010 from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085476.

Mitchell, S.L., Teno, J.M., Kiely, D.K., Shaffer, M.L., Jones, R.N., Prigerson, H.G., Volicer, L., Givens, J.L. & Hamel, M.B. (2009) 'The clinical course of advanced dementia', *New England Journal of Medicine*, 361(16): 1529-1538.

Mitchell, W. & Glendinning, C. (2007) *A Review of the Research Evidence Surrounding Risk Perceptions, Risk Management Strategies and their Consequences in Adult Social Care for Different Groups of Service Users*, York: Social Policy Research Unit. Retrieved 29 July 2010 from http://www.york.ac.uk/inst/spru/pubs/pdf/risk.pdf.

Morgan, K. (2009) 'Risks of living with Alzheimer's disease: a personal view', *Journal of Adult Protection*, 11(3): 26-29.

Morgan, S. (2004) 'Positive risk-taking: an idea whose time has come', *Health Care Risk Report*, 10(10): 18-19.

Murphy, J., Gray, C.M. & Cox, S. (2007) *How Talking Mats can help people with dementia to express themselves* York: Joseph Rowntree Foundation. Retrieved 23 August 2010 from http://www.jrf.org.uk/sites/files/jrf/2128-talking-mats-dementia.pdf.

Muster, D. (1997) 'The ambiguous nature of the terms hazard, risk and danger as they are used by the lay public, technologists and attorneys', *Technology, Law and Insurance*, 2(1): 21-31.

Naidu, A. & McKeith, I.G. (2006) 'Driving, dementia and the Driver and Vehicle Licensing Agency: a survey of old age psychiatrists', *Psychiatric Bulletin*, 30(7): 265-268.

National Collaborating Centre for Mental Health (2006) *A NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care. National Clinical Practice Guideline Number 42*, London: British Psychological Society and Gaskell. Retrieved 29 July 2010 from http://guidance.nice.org.uk/cg42/guidance/pdf/English.

National Institute on Aging (2009) *Home Safety for People with Alzheimer's Disease*, Bethesda, MD: National institute on Aging. Retrieved 25 February 2010 from http://www.nia.nih.gov/NR/rdonlyres/A86CA4FA-CAA9-4E8A-8B38-F5887EFABF2B/0/HomeSafetyFINAL_08DEC.pdf.

Neill, M., Allen, J., Woodhead, N., Sanderson, H., Reid, S. & Erwin, L. (2009) 'A positive approach to risk requires person-centred thinking', *Tizard Learning Disability Review*, 14(4): 17-24.

Nuffield Council on Bioethics (2009) *Dementia: ethical issues*, London: Nuffield Council on Bioethics. Retrieved 29 July 2010 from http://www.nuffieldbioethics. org/fileLibrary/pdf/Dementia_report_for_web.pdf.

Oliver, D., Britton, M., Seed, P., Martin, F.C. & Hopper, A.H. (1997) 'Development and evaluation of evidence based risk assessment tool (STRATIFY) to predict which elderly inpatients will fall: case-control and cohort studies', *British Medical Journal*, 315(7115): 1049-1053.

Oliver, D., Daly, F., Martin, F.C. & McMurdo, M.E.T. (2004) 'Risk factors and risk assessment tools for falls in hospital in-patients: a systematic review', *Age and Ageing*, 33(2): 122-130.

Owen, T. & Meyer, J. (2009) *Minimising the Use of 'Restraint' in Care Homes: challenges, dilemmas and positive approaches*, London: Social Care Institute for Excellence. Retrieved 29 July 2010 from http://www.scie.org.uk/publications/ reports/report25.pdf.

Pawson, R., Boaz, A., Grayson, L., Long, A. & Barnes, C. (2003) *Types and Quality of Knowledge in Social Care*, London: Social Care Institute for Excellence. Retrieved 15 June 2010 from http://www.scie.org.uk/publications/ knowledgereviews/kr03.pdf.

Powell, J., Chiu, T. & Eysenbach, G. (2008) 'A systematic review of networked technologies supporting carers of people with dementia', *Journal of Telemedicine and Telecare*, 14(3): 154-156.

Powell, J., Gunn, L., Lowe, P., Sheehan, B., Griffiths, F. & Clarke, A. (2010) 'New networked technologies and carers of people with dementia: an interview study', *Ageing & Society*, 30(6): 1073-1088.

Pratt, R. & Wilkinson, H. (2003) 'A psychosocial model of understanding the experience of receiving a diagnosis of dementia', *Dementia*, 2(2): 181-199.

Qureshi, H. (2009) *Restraint in Care Homes for Older People: a review of selected literature*, London: Social Care Institute for Excellence. Retrieved 29 July 2010 from http://www.scie.org.uk/publications/reports/report25.pdf.

Robins, J. (2010) 'Financial planning for the worst', *The Observer*, 4 July 2010. Retrieved 23 August 2010 from http://www.guardian.co.uk/lifeandstyle/2010/jul/04/planning-for-dementia-advice.

Robinson, L., Clare, L. & Evans, K. (2005) 'Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples', *Aging & Mental Health*, 9(4): 337 – 347.

Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K. & Bond, J. (2007) 'Balancing rights and risks: conflicting perspectives in the management of wandering in dementia', *Health, Risk & Society*, 9(4): 389-406.

Rowe, M., Feinglass, N. & Wiss, M. (2004) 'Persons with dementia who become lost in the community: a case study, current research, and recommendations', *Mayo Clinic Proceedings*, 79(11): 1417-1422.

Rowe, M.A. (2003) 'People with dementia who become lost: preventing injuries and death', *American Journal of Nursing*, 103(7): 32-39.

Samsi, K. & Manthorpe, J. (2010) "I live for today': a qualitative study investigating older people's attitudes to advance planning', *Health and Social Care in the Community*. advance access, 16 Sept. DOI: 10.1111/j.1365-2524.2010.00948.x

Sells, D. & Shirley, L. (2010) 'Person-centred risk management: The traffic light approach', *Journal of Dementia Care*. 18(5): 21-23.

Social Care Institute for Excellence (2009a) *E learning resource: Managing risk, minimising restraint: Challenges, dilemmas and positive approaches for working with older people in care homes*, London: Social Care Institute for Excellence. Retrieved 29 July 2010 from http://www.scie.org.uk/publications/elearning/restraint/index.asp.

Social Care Institute for Excellence (2009b) '*Raymond's money*', Social Care TV. Retrieved 29 July 2010 from http://www.scie.org.uk/socialcaretv/video-player.asp?guid=ee0c0eb4-51cc-4486-9add-3bfb8c2fd214.

Stanley, N. & Manthorpe, J. (2009) 'Small acts of care: exploring the potential impact of the Mental Capacity Act 2005 on day-to-day support', *Social Policy and Society*, 8(1): 37-48.

Starkstein, S.E., Garau, M.L. & Cao, A. (2004) 'Prevalence and clinical correlates of disinhibition in dementia', *Cognitive and Behavioral Neurology*, 17(3): 139-147.

Starkstein, S.E., Jorge, R., Mizrahi, R., Adrian, J. & Robinson, R.G. (2007) 'Insight and danger in Alzheimer's disease', *European Journal of Neurology*, 14(4): 455-460.

Taylor, B. (2010) *Professional Decision Making in Social Work*, Exeter: Learning Matters Ltd.

Taylor, B.J. (2006) 'Risk management paradigms in health and social services for professional decision making on the long-term care of older people', *British Journal of Social Work*, 36(8): 1411-1429.

Taylor, B.J. & Donnelly, M. (2006) 'Professional perspectives on decision making about the long-term care of older people', *British Journal of Social Work*, 36(5): 807-826.

Titterton, M. (2004) *Risk and Risk Taking in Health and Social Welfare*, London: Jessica Kingsley Publishers.

Tulloch, J. & Lupton, D. (2003) *Risk and Everyday Life*, London: Sage Publications Ltd.

UK Wandering Network (2005-2009) *UK Wandering Network (UKWN)* Retrieved 1 March 2010 from http://wanderingnetwork.co.uk/Welcome.htm.

Vassallo, M., Mallela, S.K., Williams, A., Kwan, J., Allen, S. & Sharma, J.C. (2009) 'Fall risk factors in elderly patients with cognitive impairment on rehabilitation wards', *Geriatrics & Gerontology International*, 9(1): 41-46.

Walker, A.E., Livingston, G., Cooper, C.A., Katona, C.L. & Kitchen, G.L. (2006) 'Caregivers' experience of risk in dementia: The LASER-AD Study', *Aging & Mental Health*, 10(5): 532-538.

Walker, W. (2004) 'Promoting a safe environment for confused older people at risk from falling in hospital', *Journal of Orthopaedic Nursing*, 8(2): 72-76.

Wang, X.T., Kruger, D.J. & Wilke, A. (2009) 'Life history variables and risk-taking propensity', *Evolution and Human Behavior*, 30(2): 77-84.

Waugh, F. (2009) 'Where does risk feature in community care practice with older people with dementia who live alone?', *Dementia*, 8(2): 205-222.

Whitman, L. (ed) (2010) *Telling Tales about Dementia: experiences of caring*, London: Jessica Kingsley Publishers.

Williams, S. & Keady, J. (2006) 'Editorial: The narrative voice of people with dementia', *Dementia*, 5(2): 163-166.

Woods, B. (1999) 'Promoting well-being and independence for people with dementia', *International Journal of Geriatric Psychiatry*, 14(2): 97-105.

Wright, C.F., Hall, A., Matthews, F.E. & Brayne, C. (2009) 'Biomarkers, dementia, and public health', *Annals of the New York Academy of Sciences*, 1180(Biomarkers in Brain Disease): 11-19.

DH *Department of Health*