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HOW CAN 'POSITIVE RISK-TAKING' HELP BUILD DEMENTIA-FRIENDLY COMMUNITIES?

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This *Viewpoint* explores how 'positive risk-taking' can help communities become dementia-friendly. This concept challenges us to think differently about risk for people living with dementia. How can we use its principles to inform understanding of dementia and change attitudes? How can we achieve the benefits and meet the challenges of applying it in practice?

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Background

The main audiences for this *Viewpoint* are: the broad range of people and services in communities that people living with dementia come into daily contact with, and some of those living with dementia, their families and friends.

The concept of 'positive risk-taking', the idea that measuring risk involves balancing the positive benefits gained from taking risks against the negative effects of attempting to avoid risk altogether, first developed in statutory mental health services. We argue that it applies equally to everyday situations, decisions in informal supportive relationships, and decisions involving the wider local communities of non-care/health public sector services, commercial businesses, community groups and the general public.

Assessing and managing risks for people who use health and social care services because of mental illness or dementia can dominate everyday practice. Concerns exist around people being a danger to themselves (both through intentional self-harm or self-neglect) or a danger to others. In this context, risk is defined negatively and it is appropriate to focus on minimising risk. 'Positive risk-taking' has developed over the last 20 years (Morgan, 1996; 2013) and recognises that the negative consequences of risk must be managed appropriately. But it sees risk as also providing opportunities for learning and enabling people to make their own decisions, to exercise choice. It builds upon individual strengths and abilities rather than focusing on deficits.

In this *Viewpoint* we explore:

- the relevance and application of these ideas to current policy and practice aimed at making communities more dementia-friendly;
- the barriers presented by official terminology, which rarely reflects the language people use every day; and
- recommendations for embedding 'positive risk-taking' into the daily experiences of people living within their local communities or neighbourhoods.

Key points

- The focus of positive risk-taking is on making good decisions about risk; it is the taking of calculated and reasoned risks, not leaving things to chance.
- There is no such thing as a risk-free decision; the risk-averse, apparently safe, option comes with its own risks.
- It is all too easy to see the negatives and deficits around someone living with dementia and to remain oblivious to their capabilities and potential and those of the resources they may have around them.
- Making decisions is exercising power; other people (however well-meaning) often deny people living with dementia this power.
- The term 'community' is often ill-defined and abstract. We are dealing with individuals; only they can define their own communities. The term 'neighbourhood' may make more sense to many people.
- A dementia-friendly neighbourhood or community will be good for everyone; it is not just about accommodating people living with dementia.
- Dementia-friendly neighbourhoods or communities are not risk-free.
- Clarity in language enables clarity in thinking; the concepts emerging in health and social care services have wider application, but not if presented in impenetrable jargon.

Introduction

Dementia indiscriminately affects many different types of people – from political leaders to shop assistants, business owners to mechanics and entertainers to cleaners. In our ageing society, an increasing number of people are living with a form of this illness and, as we live longer, our chances of developing it increase. How can we take calculated risks to boost our odds of a good quality of life whether or not we are living with dementia?

The concept of 'positive risk-taking' is all about sharing risk. Making decisions and managing risks should be a neighbourhood or community responsibility, not a burden for a single individual. Faced with a decision alone, most people will be risk-averse: if something goes wrong it will be our fault and our responsibility. Sharing that decision helps us think through the options more clearly from different perspectives. This doesn't mean we will always take the risk. There will always be situations where we must accept that avoiding risk is the best choice. It does mean we can always be confident that any decision has been carefully thought through.

Whatever condition people are living with, they still have strengths to call upon – their own qualities, capabilities and wishes, as well as their personal history of experience. Many will have a supportive network of family and friends. The challenge is for the wider community – services and businesses – to support people to live with dementia in the ways that they choose.

What do we mean by 'positive risk-taking'?

Concerns about risk involving people living with dementia arise for a number of reasons. Two are particularly relevant here.

First, there is the (actual or perceived) disability/frailty caused by dementia, other illnesses and age. Individuals, family and friends, staff and others providing paid care or support might all have concerns. The person themselves may seem to be at risk (e.g. as the victim of crime, having an accident or getting lost) or to pose a risk to others (e.g. leaving taps running, causing an accident).

Second, a risk-averse or paternalistic culture exists in many health and social care services. This is a longstanding criticism, but culture change has proved hard (see House of Lords, 2014). Clearly, services must take a balanced approach. But increased emphasis on adult safeguarding, concerns about professional and organisational reputations, and fear of media repercussions have tended to reinforce risk aversion.

Author Erica Jong said: *"If you don't risk anything, you risk even more."* One common stereotype is that people living with dementia are hardly 'living' at all. Our biggest risk could be not taking a risk. This challenges us to think beyond what may seem the simple option of avoiding an obvious risk. But, immediately, a couple of important questions arise:

- What do we mean by taking risks in connection with people living with dementia?
- How should we go about trying to take *calculated* risks?

The concept of 'positive risk-taking' developed in adult mental health services in the mid-1990s (Morgan, 1996). It offered a more sophisticated approach to assessing and managing risks with people who largely felt health and social care services were irrelevant to their needs. In many cases, these were people who were able to articulate quite clearly what they wanted. Their decisions involved degrees of risk, but some of the most obvious dangers were less likely to happen because the person had very good reasons to try to avoid them.

'Positive risk-taking' emerged as a way of describing the thinking that goes into these types of decisions. It means what it says: what we are doing is 'taking risks' to achieve our own personal 'positive outcomes'. We all take risks every day. Mostly we do so in order to benefit from what it is we want to do – we aim for clear positive outcomes. The term 'positive' is not about the risk, but about the *outcome* of taking a risk.

This concept is very specific. If our language is vague, different people can make different interpretations of what a word or phrase means:

- Terms such as 'positive risk', 'positive risk management' and 'risk enablement' remain too general and open to different interpretations.
- 'Positive risk-taking' is a clear statement of action and intent.

For many people with dementia the minutiae of daily life may be as important as service arrangements – going shopping, using power tools, driving, trusting people to help with chip-and-pin technology, holding onto an identity, finding a purposeful role. Positive risk-taking can influence power relationships in the complex area of private and public lives. One neighbour is understanding and supportive, another fearful and restricting. All need better information in order to exercise their power responsibly without feeling they are solely responsible.

What do we mean by 'dementia-friendly communities'?

There have been moves to make communities more 'dementia-friendly' around the world over the last ten years. These range from local, small-scale initiatives to national dementia policies.

In England, the *Prime Minister's challenge on dementia* included a commitment to make communities more dementia-friendly (Department of Health, 2012). This encompasses businesses (such as banks and supermarkets), faith communities and third-sector organisations. *Scotland's national dementia strategy* contains a commitment to dementia-friendly communities (Scottish Government, 2013), with the Dementia Services Development Centre (DSDC) at the University of Stirling very active. Wales' national strategy for dementia refers to 'dementia supportive communities' in its subtitle (Welsh Assembly Government & Alzheimer's Society, 2011). Dementia-friendly community work is taking place in Northern Ireland (also supported by the DSDC and the Alzheimer's Society). National organisations, such as the Joseph Rowntree Foundation (JRF) and the Alzheimer's Society, have taken a lead on much of this, although there are numerous local initiatives (Innovations in Dementia, 2012).

'Community' can seem an ill-defined and abstract idea. Statutory and voluntary sector services use it to describe many different types of geographical area or groups of people. JRF uses a working definition of the idea as *"... one in which every person with dementia, and their families, feels included, welcomed, supported, listened to and understood"* (Joseph Rowntree Foundation, 2013). The concept of being 'dementia-friendly' incorporates:

- Greater public awareness of dementia, and how to relate to people living with dementia.
- People's openness to being supportive to those living with dementia (such as their neighbours or customers).
- Being more inclusive, encouraging people to remain active in society.

In this paper, we are talking about individuals who happen to be living with dementia; only they can accurately define what 'community' means to them. It is who and what they relate to locally. Many people will think of this as their local 'neighbourhood'; others might say they live in a 'community'. For one person, their neighbourhood or community might be the corner shop and a friendly neighbour. Another may define it more widely, as family and networks around a local church, pub, community centre or shopping centre.

A further debate could be had around this language. Talking of being 'age-friendly' could be a more inclusive approach to changing attitudes. It applies to all of us living long enough to age, not just those who will develop dementia. It could engage people who have not been diagnosed with dementia but fear the label. Any problems they experience become part of ageing, not necessarily a precursor to dementia. One drawback to this approach is that it excludes younger people with early-onset dementia.

Dementia is a progressive condition and brings challenges. Ultimately, we are asking people living with dementia, and those around them, to decide what they want to do or how they want to be. This is about having the power of choice to be as active or inactive as you wish, to retain an established identity or to continue to take on new challenges.

How can we put risk-taking into practice?

Linking positive risk-taking with dementia was flagged up in the practice guidance, *Nothing ventured, nothing gained* (Department of Health, 2010). The Care Act 2014 could lead to more positive risk-taking approaches. Its vision of people managing their own flexible personal budgets to pay for their support opens up all manner of potential choices. However, many unpaid carers (family and friends) may have concerns about personal budgets if they feel they (and the person in receipt of care and support via the personal budget) will be left largely unsupported by services yet at the same time having some responsibility for organising and providing the person's care and support.

When we consider taking a risk with someone who is living with dementia we are essentially helping them, and others around them, to weigh up the pros and cons of their choices in a particular decision. There will always be risks attached to any option. The task is to see if the benefits outweigh the risks for one choice rather than another. This concept can be applied to any scale of decision (see Box 1).

These types of decisions are not easy, they require:

- Everyone who will be reasonably affected by the decision to be involved, in varying capacities.
- Information and detailed thinking throughout, with a plan to manage the likely risks of whatever option is chosen.
- Clear knowledge of the person's abilities and level of understanding of the risks.
- Clear understanding of the benefits a person gains in terms of a positive outcome from taking a specific risk.
- A good plan in place, with the support that can reasonably be made available, so the person taking a risk feels as safe as possible.
- Anticipation of how things could go wrong, with a reasonable crisis response or contingency plan in place.

Things will occasionally go wrong. All of us – family, neighbourhood, community, services and the media – should acknowledge that this happens in all our lives. Fear and blame are the least helpful responses, particularly if the original decision and subsequent actions were reasonable.

In our lucid years, we should reflect on what we might choose if we did develop dementia. Would we value a potentially shorter life lived with personal control, choice and enjoyment over a potentially longer life of comparative inactivity and lived under restriction? Ask yourself: would you take a risk?

Box 1: Three scenarios for positive risk-taking

- Doreen lives in her home of many years. She still wants to go to her favourite local pub. We should help her weigh up the dangers of road safety, getting lost, and losing money against those of becoming a prisoner in her own home with reduced activity, interaction and stimulation, plus the loss of another role she's long had in her life.

- Felix is becoming increasingly forgetful and has been found wandering lost in the local area. If Felix went into a care home, he could be supervised and supported. But if he wishes to stay in his home for longer, other resources could support him. These might include advances in telehealth and telecare. It could mean engaging family, neighbours and other local people. Will they accept his wandering behaviour if he can be easily guided back home when needed? Are they available to support Felix and keep an eye on him? What are the risks in making this choice?

- June lives in a care home but would like to make herself a cup of tea and a simple snack when she wants. The home has a blanket policy on health and safety grounds: everyone has tea made by a staff member or volunteer at set times. What are the risks that June might harm herself with hot or sharp implements? Does she understand these? Are these greater than the risks to her of inactivity and loss of skills and independence?

The dangers in the safe option

A safe life may be a cosseted life, but does it offer good quality of life? It is very easy to generalise about dementia, particularly if we focus on worst-case examples. These are real and remind us of possible dangers. But we can't base policy about dementia-friendly communities on these alone: each circumstance requires an individual response.

The most common 'safe option' will be removing a person from their own home and placing them in a care home with greater support and security. For many people living with dementia, a time will come when a care home is the best option.

We should be encouraging everyone to view the care home as part of the local community, not as somewhere apart where people are warehoused until they pass away unnoticed. However, even with the best intentions and staffing, the 'safe option' holds risks. We are taking someone with diminishing mental capacity out of a familiar place and putting them into a completely unfamiliar environment.

Care homes frequently operate on the basis that 'doing to' and 'doing for' residents reduces risks or even in the false belief that it eliminates risk. Such risk aversion ironically runs its own risk of depriving people of mental stimulation and retention of basic skills. This could in turn hasten mental deterioration and other associated physical conditions. Dignity diminishes as the person with dementia experiences less choice, with little respect for their own wishes, past or present. All of us should envisage our life with dementia. What would we want it to look like? What risks would we accept to achieve it? Now consider people currently living with dementia. What would they have wanted their life to look like? What would they choose now if they could?

What is a 'strengths approach'?

'Positive risk-taking' relies heavily on a 'strengths approach'. First and foremost, this is a way of encouraging us to think of what we 'can do' before we take the simpler option of seeing a condition and thinking 'can't do'. For most people living with dementia, the daily experience of meeting others can be one long catalogue of what you aren't doing, can't do, haven't done and should be doing. If you are really unlucky, it will go into historical detail of all the other times you weren't doing what you should be doing. It might even conclude with the things you should be doing in the future that you may not even want to do. All in all, a very depressing prospect. We need to see everyone in terms of their strengths – their personal qualities, abilities, capabilities, desires, motivations, dreams and wishes. We all have strengths but they are not always obvious; sometimes the biggest challenge is searching for them (Morgan, 2014).

Our strengths draw on our past, as well as our current situation and future priorities. For many people living with dementia, this is about discussing favourite places, people, foods, activities and routines. It is about those close to them knowing their personal wishes and priorities. It is about identifying the people close to them and in the community who can, and wish to, act as sources of support. It is ultimately about enabling people to live with as much dignity as possible. Their identity is 'who they are' and 'what they can do', not 'what they are' and 'what they can no longer do'.

We are all more confident taking a risk if we know what motivations, capabilities and resources will help us achieve the positive outcomes we desire. The same applies to our confidence in supporting a person living with dementia to take a risk; part

of weighing the pros and cons of different options is understanding the presence or absence of strengths in each available choice. In doing this, we'll have travelled a long way to making that reasoned decision.

What needs to happen?

For dementia-friendly communities to thrive, the concept of 'positive risk-taking' needs to be put into practice. This is about giving people information and means to support their confidence in managing real and perceived risks within their local neighbourhoods or communities. It is not about services abdicating responsibility and redirecting full responsibility to families and neighbours. It is about helping local people to engage better with statutory services when needed. It is not about relying on those individuals, most often women, who accept caring roles while everyone else steps back. A dementia-friendly community is one in which more people share the perceived burden or responsibilities for care and support and challenge fears about giving more power and choice to people living with dementia.

How will the principles and practice of positive risk-taking help achieve this?

- **Bust the myths.** Develop simple means of communicating information about dementia and the possibilities for living with it to people in local neighbourhoods or communities.
- **See the individual.** Be clear about who needs to be engaged in the discussions and decisions regarding individuals, be specific about what individuals need, don't generalise about groups of people.
- **Identify and celebrate risk-takers.** Develop local lists of recognised dementia-friendly people, organisations and services.
- **Break down stigma.** Consider offering a crisis card or pendant to local people living with dementia. There are now well-recognised symbols for individuals, services and businesses to use that denote they are 'dementia friendly' and these could be incorporated into the crisis card or pendant.
- **Provide a safety net.** Consider how local emergency services can hold an up-to-date list of local residents living with dementia, and how they should respond, generically and specifically, if needed.
- **Support decision-making.** Distribute a simple checklist to support positive risk-taking:
  - Have you got the accessible/useful information you need?
  - What are the risks associated with each available choice?
  - What risk is being taken (and by whom)?
  - What are the positive outcomes of taking the risk?

- What strengths can be identified?
- What steps need to be taken to manage the risk-taking?
- What could go wrong, and how could that best be managed?
- Accept that some things can go wrong: who can help manage the fear or guilt?

Conclusion

A dementia-friendly community is above all about people accepting the behaviours and challenges of some members of society. Each of us has an increasing risk of developing dementia; tolerance of those currently wrestling with diminishing abilities is an investment in a society that will take the risk to support us in the future.

Creating comparative safety for people living with dementia lies in a mix of design of the built environment and prevailing social attitudes. Fostering familiarity with the neighbourhood, and avoiding too much artistic confusion in new product or building design, might be easier to influence. Changing attitudes is often more difficult. But the principles of positive risk-taking help shift the focus of thinking. They help inform what is possible rather than assuming things are impossible. Taking risks will not always be about helping people to change and strive for the new; with diminishing memory, thinking and reasoning, positive risk-taking will be as much about familiarity and using personal strengths. It is about seeing what you still have rather than simply seeing what you have lost.

About this paper

This paper was written by Steve Morgan, from Practice Based Evidence, and Toby Williamson, Head of Development & Later Life at the Mental Health Foundation. It offers a different way of thinking about risk and risk-taking for people living with dementia. It proposes a number of ideas that could be tested and implemented within recognised dementia-friendly communities. It involved consultation with service users living with dementia, written feedback from organisations working in the field, and a roundtable discussion facilitated by the Mental Health Foundation. It is part of JRF's work promoting dementia-friendly communities.

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FOR FURTHER INFORMATION

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