



PRACTICE TOOL

Enablement in dementia

Introduction

This Practice Tool follows on from the Research in Practice for Adults Key Issue *Enablement in dementia* (Blood, 2015) to support frontline practitioners to deliver dementia services with enablement in mind.

What do we mean by 'enablement'?

Enablement is about promoting independence and improving wellbeing – principles which lie at the heart of the *Care Act 2014*.

Enabling someone involves:

'reducing the barriers that get in the way of them doing the things they want to do and being the person they are.'

(Blood, 2015)

This Practice Tool is aimed at the following people in their work with people with dementia:

- > Social workers and others involved in care and support planning and assessment.
- > Reablement/re-enablement and intermediate care workers.
- > Social care providers (care home/domiciliary care/day service staff and managers).
- > Health, clinical, community health professionals.
- > Voluntary sector and housing association support and wellbeing workers.
- > Many of the principles will also be useful to family and friends caring for people with dementia.

It will support practitioners to:

- > apply a strengths-based approach to their assessments of people with dementia
- > understand the particular considerations when assessing risks for people with dementia, including the legal framework and messages from research
- > take a positive risk-taking approach to decision-making with people with dementia.

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Links to the *Care Act 2014*

Strengths-based practice

The *Care Act 2014* requires local authorities to ‘consider the person’s own strengths and capabilities, and what support might be available from their wider support network or within the community to help’.



SCIE has produced a video on strengths-based approaches and the *Care Act* - see www.scie.org.uk/care-act-2014/assessment-and-eligibility/strengths-based-approach/care-act-video-eligibility-approach.asp

Positive risk-taking

The *Care Act 2014* shifts the focus from talking about ‘vulnerable people’ to ‘people at risk’. The *Care Act Guidance* also reinforces the principles of the *Mental Capacity Act* (see the box on page 9 and also Department of Health, 2014) requiring us to do everything practicable to enable people to make their own decisions.

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Part 1: Strengths-based approaches to working with people with dementia

The traditional approach to working with people with dementia has tended to be to react to 'deficits', problems and things that the person cannot do; to *manage* risks and to *segregate* the person (in a care home or hospital) when things get really difficult (Kitwood, 1997; Hill et al, 2010; Power, 2015).

So what does it mean to take a 'strengths-based approach'?

Strengths-based practice:

- > deploys the strengths of individuals, families, groups and organisations to empower them (Iriss, 2012)
- > is a collaborative process to identify desired outcomes (SCIE, 2015)
- > focuses on the resources in relationships and communities, and treats people as the experts on their own lives (Fox, 2013).

How can we do this?

Tool 1: What and who matters most to me

Mapping out the people, activities, places and things which matter most to a person with dementia is a good way to start an assessment, since it helps us to focus on them and their strengths and resources (rather than a form).

It can also help us to explore the person's life history, which is particularly important when working with people with dementia.

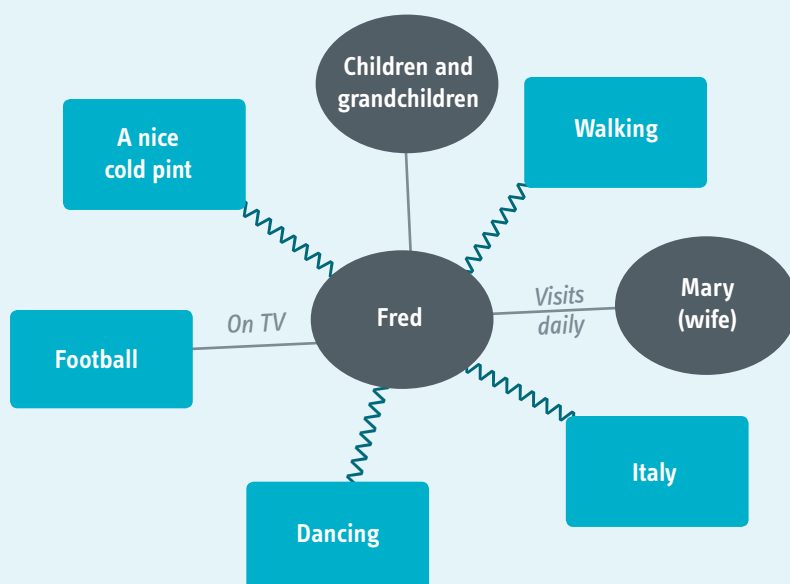
In the map below, we show Fred's world. We will tell you more about Fred later on.

Instructions:

- > Circles = people (or pets).
- > Rectangles = activities, places, things, beliefs, talents.
- > Straight lines = ongoing contact/participation.
- > Zig-zags = barriers (add short notes to explain what helps or gets in the way).

When working with a person with dementia, it is important to focus on how these things, people, places or memories make them feel. You could record this on the map too. **Remember that they may not be able to understand, remember or explain why these things or people make them feel this way.**

It will often be a good idea to include a supporter – a partner, close relative, friend or care worker - in this discussion. They could prompt the person to remember things and advise on what they can still do. **Be careful not to end up simply having a conversation with the carer in front of the person with dementia.**



Adapted from *My world* (Baim C and Morrison T, 2011)

Some of the following questions may be useful prompts:

- > What would a perfect day look like for you? Who would you spend it with?
- > What did you used to enjoy doing when you were younger?
- > What were you good at doing? What did you do for a living?
- > Which day-to-day tasks can you still do and take pride in?
- > Do you get the opportunity to help other people? (Don't assume that people with high support needs will not want or be able to help others or make a contribution.)
- > Any little pleasures that make life worth living?

To make the activity more accessible to some people with dementia, try using a set of photographs which show activities and interests. Select images which are unambiguous (for example a deck of playing cards rather than a group of people sitting around playing cards – people could misinterpret what they are doing or get distracted trying to remember the faces).

Using tools, such as talking mats - www.talkingmats.com - may also help to understand the wishes and feelings of people with moderate or severe dementia.

Another option might be to walk around the local area with the person, visiting places they go to now or used to go to in the past. 'Walking the patch' is described in the Research in Practice for Adults Practice Tool *Involving and engaging people with dementia* (Litherland, 2015):

www.ripfa.org.uk/resources/publications/practice-tools-and-guides/involving-and-engaging-people-with-dementia-practice-tool-2015

The finished map could be a way of sharing information between carers and other professionals (though sensitive information may need editing out – discuss this with the person and their family).

**Tip:**

Past experiences (for example living in Italy) can still be experienced through photos, memories, objects, food, etc. Look for simple ways to connect people with things or places that make them feel happy and safe. In Owen and Meyer (2012) a man with advanced dementia who used to be a dairy farmer felt much calmer when care home staff made sure his farming trousers were by his bed, gave him a drink of milk and talked to him about his cows.

**Further reading**

McGovern (2015) talks about working with families and couples affected by dementia to support them to focus on shared moments, feelings and what remains; rather than memories, thoughts and what is lost.

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The Senses Framework was developed for nursing staff working with older people. It encourages us to think about how older people and those working with them can achieve the following senses:

- > **Security**
You feel safe and have your essential needs met.
- > **Continuity**
You and others know your story.
- > **Belonging**
You have relationships and feel part of a community.
- > **Purpose**
You can do meaningful activities and learn.
- > **Fulfilment**
You feel good about what you do.
- > **Significance**
You feel valued as a person.

(Nolan M et al, 2006)

David Sheard's 'Butterfly Approach' - see www.dementiacarematters.com/pdf/modern.pdf - can help care homes create a strengths-based and person-centred culture.

Attachment theory can help us to support people with dementia in a strengths-based way, since it recognises that behaviours which appear 'difficult' and 'inexplicable' are actually ways of adapting to threats and dangers and can themselves be seen as strengths. Thinking about the function of people's behaviours can allow us work with them to find more positive ways to feel safe and secure. Research in Practice for Adults has produced a Frontline Briefing on *Adult attachment* (Nosowska, 2015) - www.ripfa.org.uk/resources/publications/frontline-resources/adult-attachment--implications-for-adult-social-care-practice-frontline-briefing-2015-

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Fred's story



Fred has advanced dementia and has recently moved from one care home to another. His wife, Mary (who herself is at an earlier stage of dementia), arranged this move because the previous care home would not let her take Fred out of the home on short day trips and he was becoming depressed.

The manager at the new care home is keen to find ways to improve Fred's quality of life. She sits down with the couple to map out Fred's world (see page 4). They identify many things which Fred values but has not been able to do for some time. The only things he has really enjoyed recently are Mary's daily visits and watching football (which he tends to do alone in his room).



Suggested exercise (for example to use in group training)

The Key Issue on *Enablement in dementia* (Blood, 2015) presents a wide range of ideas and resources for enabling people with dementia to reminisce, exercise, be creative, get close to nature and link into their local communities. Look through the publication and consider services/initiatives that could be utilised to enable Fred to connect with some of his other interests and passions.

What might some of the barriers and enablers be here?

Part 2: Positive risk-taking and people with dementia

'One of the biggest barriers to enabling people with dementia to have more control over their lives is an overly cautious approach to risk'.

(Manthorpe and Moriarty, 2010)

Supporting people to live well will always involve some degree of risk. In 'positive risk-taking' or 'risk enablement' we do not take these risks any less seriously. Instead we weigh them up alongside the potential positive outcomes in order to make defensible, rather than defensive decisions. After all, this is how we make decisions all the time in our own lives.

When we give too much weight to the risk of things going wrong and people getting physically hurt, we tend to ignore the 'silent harms' (Clarke et al, 2011) – of boredom, frustration or losing the fulfilment we get from doing things for ourselves. We need to protect identity, meaning and purpose in life.



Further reading

- > Research in Practice for Adults Frontline Briefing on *Risk enablement* (2016)
- > The Department of Health's *Risk guidance for people with dementia* (Manthorpe and Moriarty, 2010)

When supporting people with dementia to take positive risks it is crucial that we understand and act within the law.

Understanding and applying the law

The Mental Capacity Act (MCA) 2005: Key points

1. Assume people can make their own decisions unless proven otherwise - don't make assumptions just because they have dementia or because of their age.
2. Make every effort to support people to make the decision for themselves.
3. Everyone has the right to make unwise or unusual decisions – this, in itself, does not mean a person lacks capacity.
4. Capacity to make decisions fluctuates; decisions about capacity are specific to that time and that decision – lacking capacity is not a permanent label.
5. A person lacks the mental capacity to make their own decision if one or more of the following conditions are evidenced (it is for us to demonstrate that someone lacks capacity, not for them to demonstrate they have it).
They are unable to:
 - a. understand information given to them
 - b. retain that information long enough to be able to make the decision
 - c. weigh up the information available to make the decision
 - d. communicate their decision (by talking, sign language, muscle movement, blinking or squeezing a hand).
6. If someone is assessed as lacking capacity, we must make the decision in their best interests (drawing on their personal history, preferences and the sorts of decisions they have typically made in the past) and continue to involve them as much as possible in the process.¹
7. If this decision involves a 'Deprivation of Liberty', for example in which a person will be subject to continuous supervision and control and/or is not free to leave a place², and the person is in a care home or hospital, the local authority must authorise this under the DoLS (Deprivation of Liberty Standards). We must always aim to find the least restrictive option.



Further reading

- > *The MCA 2005: Code of Practice* - www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf
- > SCIE's MCA online directory - www.scie.org.uk/mca-directory

¹This is also reflected in the UN's *Convention on the Rights of Persons with Disabilities*

²Definition set out by the Supreme Court Judgement of March 2014: www.gov.uk/government/uploads/system/uploads/attachment_data/file/300106/DH_Note_re_Supreme_Court_DoLS_Judgment.pdf

The law in practice

The House of Lords (2014) pointed out that the *Mental Capacity Act* has ‘suffered from a lack of awareness and a lack of understanding...The empowering ethos has not been delivered’.

The courts usually rule in favour of the least restrictive option for a person. In *Cardiff County Council v Mrs Peggy Ross* (2011) the Court of Protection considered whether Mrs Ross (who was living in a care home with a diagnosis of dementia) had the capacity to decide to go on a 16-day cruise with her partner of twenty years. The care home was reluctant to let Peggy go and had delayed making a decision. The couple had been on many cruises together and professionals felt she understood that she was due to go on a cruise and what this meant but that she ‘cannot retain this information and does not have the ability to weigh up this information to make an informed decision’.

The judge ruled that Mrs Ross should go on the cruise: “Even if others believe that to decide to go on this cruise is an unwise decision, that in itself is insufficient to demonstrate that she is unable to make the decision.”

Professionals had focused too much on what might go wrong and not taken sufficient account of the potential benefits of going on this cruise, for what might be the last time. He felt Mrs Ross was sufficiently familiar with the layout and routine of cruising and that her partner was well-placed to care for her while aboard.

He concluded that:

“...this is not a life-changing decision, or a choice between two evils or a decision over which an elderly person without Mrs Ross’s impairment would be likely to agonise. It is a choice of whether to go on holiday or not, in familiar circumstances, with one’s companion of the past two decades.”

The full judgement is available at: www.mentalhealthlaw.co.uk/media/Cardiff_Council_v_Peggy_Ross_%282011%29_COP_28-10-11_12063905.pdf

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Using research evidence to inform decisions about risk

People living with cognitive conditions may be particularly vulnerable to forgetting, getting disoriented, confused, distressed or lost. Research evidence can estimate the likelihood of key risks for them; for example, people with dementia are twice as likely to fall as those without (Mitchell, 2014).

There is, however, a danger that professionals simply find the evidence to back up their views. This may (understandably) be about covering their own backs in a culture of blame and risk aversion.

In the SCIE TV video featuring Mr and Mrs Jones' case, a panel of experts commented that professionals seemed to have done just this. In making their assessment about whether Mrs Jones could be safely discharged from hospital back home to live with her husband, they had given considerable weight to the fact that Mrs Jones had 'failed' the kettle test, by putting an electric kettle onto the hob. They had not stopped to find out what type of kettle the couple had at home.

**Link to video:**

www.scie.org.uk/socialcaretv/video-player.asp?v=dols-in-light-of-the-supreme-court-judgment-practice

Using evidence to help us make more balanced, and legal, decisions could mean:

- > Looking behind the headlines to discover the particular risk factors for people with dementia falling, for example use of psychotropic/multiple medications, presence of other conditions like sight loss or osteoporosis (Mitchell, 2014).
- > Looking for evidence of the benefits of participating in activities for people with dementia as well as the risks. In the Key Issue (Blood, 2015) evidence on the benefits of physical exercise, cognitive stimulation and social interaction for people with dementia is presented.

**Tip:**

Focus on how the environment can be changed to reduce the risk, rather than stopping the activity altogether (in the hope of preventing risk altogether).

For example, if someone is keen to dance, consider moving the furniture out of the way, dancing with a support worker and dancing close enough to the sofa so the person can quickly fall onto it if they become tired, dizzy or disoriented (taken from Manthorpe and Moriarty, 2015).

Mind your language!

What language do we use when talking about people with dementia? What is the impact of this?

- > 'Wandering' (rather than 'walking' or 'taking a stroll').
- > Thinking of a person as 'vulnerable' rather than asking what the risk might be in a specific situation (a shift of approach supported by the *Care Act 2014*).
- > 'Reverting back to being a child' (rather than being an adult who is struggling to regain their place in the world).

This isn't just about being politically correct, the language we use often shapes our attitudes to risk.

Involving different perspectives in risk assessment

Different key players may have different perspectives on risk. For example, safety may be the primary concern of families (Blood and Litherland, 2015; Clarke et al, 2009). Professionals, working in a variety of care settings, may have different perceptions of risk. We may need to support them to understand their fears and to present alternative options to a residential care setting.

Research suggests that:

- > when we act alone we are more inclined to 'play it safe', since we fear we will take the blame if things go wrong (Morgan and Williamson, 2014)
- > shared decision-making – involving the person with dementia, their family and supporters and a range of professionals – tends to be better decision-making with a more positive approach to risk (Clarke et al, 2009; Manthorpe and Moriarty, 2010; Morgan and Wilkinson, 2014; Andrews et al, 2015).

Tool 3: Ten questions to support positive risk assessments



Tips

If possible, bring the key players together to work through these questions:

- > the person with dementia*
- > family members
- > health/social care workers
- > home/scheme manager, etc.

Listen to each other's perspectives and record key points and decisions.

*If the person is likely to find a group discussion stressful or problematic, an alternative would be to meet separately with them (ideally with a close supporter or advocate³). You can use some of the tools and ideas in the previous section if they cannot respond to questions verbally. However, make sure their views are sought directly and fed into the process.

Take a 'can-do' attitude and try to find creative solutions wherever possible – don't set out trying to prove that it can't be done.



The questions

Be clear about the specific activity or decision which is up for discussion, then consider the following questions:

1. What does the person want to do and why? Which positive outcomes will they get from doing it? How will *not* doing this affect them?
2. Do they have *capacity* to make this decision? The answer to this question influences the status for the rest of the discussion - are we making a best interests decision here or are we simply coming together to advise, support and problem-solve?
3. What are the specific risks? How likely are they to happen, causing what level of harm if they do? How do they compare with the 'silent harms' (Clarke et al, 2011) of not being allowed to do this? You can use the chart on the following page to plot risk of harm against quality of life (QoL):

³ Note that under the *Care Act 2014*, Pt1, S67, the local authority is required to provide an independent advocate (or IMCA) where the person would otherwise struggle to understand, retain or use information, or communicate their wishes.

High QoL		Balance carefully	Continue
	Substitute		
	Stop		
Low QoL	High risk of harm		Low risk of harm

From Manthorpe and Moriarty (2010), simplified by Clarke CL (2011)

4. What are the potential risks and benefits to family members, carers and the wider community?
5. What are our own worries? (These might be about specific risks or general concerns, like being blamed if things go wrong.)
6. How does the person with dementia feel about taking risks (now and in the past)?
7. Are there ways of doing the activity *and* reducing the risks? Are there alternatives – safer ways of meeting this need?
8. What's the bottom line?
 - a. What are the rules or conditions which we agree to follow?
 - b. What is the contingency plan (if things go wrong)?
9. Which roles and responsibilities do each of us have? Is there anyone else we need to involve?
10. Which changes should trigger a review of this decision?



Tip: What to do if there isn't time to hold a meeting

- > Assess capacity (using the MCA principles on page 9).
- > Think about the potential positive outcomes for the person and try to discuss these with them.
- > Weigh these against the risks, using the 'QoL chart'.

Positive risk-taking and safeguarding: A note for managers and commissioners

If people with dementia are being supported to be more active, it is possible that the number of safeguarding alerts (particularly in relation to care home residents) will increase.

Safeguarding in light of the *Care Act 2014* requires a 'multi-agency approach to achieving positive outcomes for people who use services' (Preston-Shoot, 2015).

The sector-led initiative *Making Safeguarding Personal* encourages a person-centred and outcomes-focused approach to safeguarding in which practitioners ask about the outcomes that matter to people at the outset, review them throughout, then check the extent to which they have been realised at the end. It is the approach to safeguarding described in the *Care Act* and it recognises that we 'all have different preferences, histories, circumstances and lifestyles, so it is unhelpful to prescribe a process that must be followed whenever a concern is raised' (Department of Health, 2014).

**Further reading**

Local Government Association website - www.local.gov.uk/adult-social-care/-/journal_content/56/10180/6074789/ARTICLE

Positive risk-taking with Fred

The three-way conversation between Mary, Fred and the care home manager revealed that Mary (who is herself in the early stages of dementia) would like to take Fred out of the care home for a walk and a pint.

**Question for discussion/reflection**

What might you and others worry about here?

Despite the concerns of some of her team, the manager is determined to find out if there is a way of supporting this to happen. She convenes a small group of people to work through the ten questions: their daughter, an occupational therapist (who assessed Fred when he moved into the care home) and a memory nurse who knows them both.

After a discussion they go out of the building to walk the potential route together. They take a scenic route through the park to an accessible pedestrian crossing, which takes them to the pub. The publican recognises Fred – he used to be his football coach. Mary explains that she and Fred would like to come and have an occasional drink here, but that they may sometimes need a bit of support to do this.

They discuss the possible risks, that Fred and Mary might:

- > drink too much alcohol
- > not be able to cross the road safely
- > get lost or disoriented enroute to the pub or on their way home.

Mary suggests that, if the bar staff leave the glasses on their table, it will help them remember how much they have drunk. The publican suggests that if they have had more than two alcoholic drinks he will point this out to them and suggest they switch to a soft drink. He asks what he should do if Fred or Mary seem to be intoxicated. The care home manager gives him her number and says the home would be happy to pay for a taxi or that a member of staff could come out in an emergency. She also tells him that he and his team can request a free training course to explain the basics of dementia from the Dementia Friends scheme - www.dementiafriends.org.uk/WEBArticle?page=what-is-a-friend#.VlCdSyTA4k8

Mary and Fred agree that they will stick to this route and return to the home if the crossing is not working. The care home says they will ring Mary's mobile phone once an hour while they are out, just to check they are alright. Mary also agrees to enable the GPS on her mobile phone so that her daughter can track her whereabouts if there are serious concerns.

They all agree that they will meet again to review the plan if Mary's dementia symptoms get worse, if Fred's mobility and balance deteriorate or if there are any changes to the route.



Question for reflection

Which of the MCA principles from page 9 were applied here and how?

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