

leading for outcomes

dementia

summary

what is this guide?

Leading for outcomes: dementia seeks to explore how staff can be supported to effectively practice an outcomes-focused approach within the context of dementia. It provides information about dementia including key policies and legislation as well as signposts to other relevant resources. The guide contains a number of exercises, each with supporting training materials for leaders to use and adapt as appropriate. It will focus on the complexities dementia poses to an outcomes-focused approach, including issues of mental capacity, risk, communication impairment, different living contexts and the important role of the carer. It is intended for use by anyone working with people with dementia and their carers across the social services sector in Scotland.

This guide is part of the IRISS Leading for outcomes series designed to support team leaders, managers and trainers to lead social services teams in the adoption and implementation of an outcomes-focused approach. Leading for outcomes: a guide¹ gives general evidence-based advice and support in leading this approach within the context of adult services.

1 Freely available here: <http://www.iriss.org.uk/resources/iriss-leading-outcomes-guide>

terminology

'Dementia' is an umbrella term that is used to describe the loss of intellectual functions and will be used throughout this guide to refer to all types of dementia. The cause in over half of affected people is Alzheimer's disease, where brain cells shrink and die. The second most common cause is vascular disease where the blood supply to brain cells has been cut off. There are other causes including alcohol related brain damage, dementia with Lewy bodies (DLB), fronto-temporal dementia, Creutzfeldt-Jakob disease and HIV-cognitive impairment.

Dementia is progressive and irreversible. The stages of dementia will be described in this guide as 'early', 'middle' and 'late' as outlined by the Alzheimer's Society². Although these descriptions are broad, every person with dementia is different and their experiences of the journey with dementia will also be different³. Therefore, users of this guide are encouraged to tailor the training materials to real life scenarios wherever possible.

The term 'carers' will be used in this guide to refer to unpaid / family carers unless otherwise stated.

The term 'staff' will be used to refer to those working with people with dementia and their carers.

2 <http://alzheimers.org.uk>

3 The dementia journey: <http://www.scie.org.uk/publications/windowsofopportunity/journey/index.asp>

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part one

introduction to dementia



1.1

facts and figures about dementia in Scotland

It has been estimated that there were around 71,000 people with dementia in Scotland in 2010 and the number is set to double in the next 25 years. More than half are female and the older a person is, the more likely they are to have dementia. About a quarter of those over 85 have dementia, whether they live at home or in a care home. People of working age can also have dementia, and a very small number of children are affected. Around 2,300 people with dementia in Scotland are under 65.⁴

The changes that take place in a person with dementia include:

- > A deterioration in the ability to carry on with basic every day activities
- > Physical changes such as visual deterioration/disturbance, fatigue, changes to mobility, co-ordination and perception

- > Changes in social behaviour, like apathy and social withdrawal
- > Memory problems
- > Behaviour such as aggression, wandering (also referred to as 'purposeful walking') or sleeplessness

A person with dementia is often aware that they have a problem, but may not seek help. Even those around them who can see the difficulties are often reluctant to raise the issue or approach the family doctor. Dementia can progress slowly over several years, although this can vary. In the early stages the person may be very fit and active, and as the disease progresses may become more dependant on others for care.

Mild cognitive impairment (MCI) looks and feels much like the early stages of dementia. Many people with MCI never get dementia. However, everyone who suffers with dementia seems to go through a period of MCI. An older person who has an infection, depression or other physical conditions may also show some cognitive impairment, which looks like dementia for a time. If treated, the cognitive symptoms go away. If they already had dementia, other illness or depression may make their existing cognitive impairment seem worse until the illness or depression is treated.

⁴ *Dementia UK* Consensus prevalence rates of dementia from Alzheimer Society (2007) A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and London School of Economics.

1.2 policy context

The Dementia UK report⁵ showed policy makers in 2007 that more is spent on dementia in the UK than on cancer, heart disease and stroke put together. In spite of this high spend, media coverage of dementia has been dominated by stories of abuse and neglect, often reflecting badly on care homes, or health and social care staff.

Soon after the report was published, the Scottish Government formed a Dementia Forum, chaired by the Health Minister. This was a group of experts, including people with dementia from the Scottish Dementia Working Group⁶, who advised on high impact changes aimed to improve care and support for people with dementia and their carers. One particular change was around NHS Boards being told to increase the number of people with dementia (with a formal diagnosis) by 30%. As a result, many more people are now aware that they have dementia. They and their carers have raised expectations of care services.⁷ For example, one Scottish NHS Board calculated that it had probably 8,000 people with dementia, which was worked out using prevalence statistics.⁸ Only 4,000 were known to the health services to have dementia in that NHS area

according to the numbers on the dementia register kept by GPs. It was apparent that 4,000 other people with dementia were 'missing'. They were probably known as receivers of health and social services but because nobody had identified that they had dementia they were missing out on potential positive benefits. When this NHS Board (which covered four Local Authority areas) met its target (30%), it increased the number diagnosed by 1,200.

The benefit was that 1,200 more people and their carers:

- > Had a better understanding of why they had been having problems
- > Were offered medications to help their symptoms
- > Could be given the contacts for local peer support organisations
- > Were provided with a 24 hour helpline number (0800 808 3000)
- > Had an opportunity to make legal provision for the future
- > Could be advised on helpful design and assistive technology for their homes

5 Alzheimer Society (2007) *Dementia UK* available at http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=342

6 Find out about the Scottish Dementia Working Group, the independent influential group of people with dementia, on www.sdwg.org.uk

7 A summary of Scottish Government action on dementia from 2008: <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH/dementia>

8 An estimate of the number of people with dementia in your Scottish local authority area: <http://www.vhscotland.org.uk/library/vol/dementiastats09.pdf>

1.2 policy context / continued

- > Could warn health care staff of their special needs if they went into hospital
- > Had access to carers' support and allowances
- > Could expect social care services to understand their needs.

Following this, in 2009 the Scottish Government consulted on a national dementia strategy. It planned to:

- > develop and implement standards of care for dementia, drawing on the Charter of Rights produced by the Scottish Parliament's Cross Party Group on Dementia⁹;
- > improve staff skills and knowledge in both health and social care settings;
- > provide integrated support for local change, through the implementation of the dementia care pathway standards and through better information about the impact of services and the outcomes they achieve;
- > continue to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support;
- > ensure that people receiving care in all settings get access to treatment and support that is

appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication; and continuing to support dementia research in Scotland.¹⁰

In February 2011, the Scottish Government asked the Mental Welfare Commission for Scotland to facilitate the development of standards for care as set out in Scotland's National Dementia Strategy. People with dementia, carers and Alzheimer Scotland are part of a steering group taking this forward.

Other key policy drivers that support an outcomes-focused approach include an emphasis on living well after a diagnosis of dementia¹¹ and ensuring more effective post-diagnostic support including "access to information about dementia, therapeutic support to help with emotional adjustment, support to self-manage the symptoms, help with legal, financial and future care planning, and access to peer support"¹². 'Re-ablement', whereby people (including those with dementia) are supported to regain life skills and independence after an illness or following a stay in hospital, further promotes the view that people can live well with dementia if they receive the right support, build on their own personal resources¹³ and are empowered not to see dementia exclusively in terms of deficits.

⁹ Charter of Rights: <http://www.dementiarights.org/charter-of-rights/>

¹⁰ Scotland's National Dementia Strategy (2010): <http://www.scotland.gov.uk/Publications/2010/09/10151751/0>

¹¹ *Facing dementia: how to live well with your diagnosis*, Health Scotland, 2008

¹² *Scotland's National Dementia Strategy*, Scottish Government, 2010, p24

¹³ Personal resources: <http://www.scie.org.uk/publications/windowsofopportunity/personalresources/index.asp>

1.3 key legislation

The Adults with Incapacity (Scotland) Act 2000¹⁴ and the Adult Support and Protection (Scotland) Act 2007¹⁵ are key pieces of legislation relevant to people with dementia, their carers and those who work with them.

The Adults with Incapacity (Scotland) Act 2000 'provides a framework for safeguarding the welfare and managing the finances of adults who lack capacity due to mental disorder or inability to communicate'. Capacity is not an 'all or nothing' issue and it may be that people only need support to make particular decisions, for example, help with financial matters.

The Act is underpinned by five principles which support the person's involvement in making decisions about their own lives in so far as they are able to do so. These principles must also be followed by anyone authorised to make decisions on behalf of someone with impaired capacity, for example, someone with Guardianship or Power of Attorney.

Five principals of the Adults with Incapacity (Scotland) Act 2000

- Benefit – any action or decision taken must benefit the person
- Least restrictive option – any action or decision taken should be the minimum necessary to achieve the purpose
- Take account of the wishes of the person – account must be taken of the present and past wishes and feelings of the person
- Consultation with relevant others – take account of the views of others with an interest in the person's welfare
- Encourage the person to use existing skills and develop new skills

The Adult Support and Protection (Scotland) Act 2007 seeks to protect 'adults at risk' from harm, including those who might be more vulnerable because of disability, illness or mental disorder (e.g. people with mental health problems, people with dementia and people with a learning disability).

14 A short guide to the Act is available here: <http://www.scotland.gov.uk/Publications/2008/03/25120154/0>

15 <http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/legislation>

part two

outcomes and dementia

2

Part 1 of *Leading for outcomes: a guide* provides an introduction to an outcomes-focused approach. It will be useful to review this to ensure that you and your team are comfortable with the concept of, and terminology, associated with an outcomes-focused approach and how it differs from more 'service-led' approaches. In short, outcomes are the impact of support on one's life. The policy drivers, benefits and challenges are also discussed in *Leading for outcomes: a guide*.

Outcomes important to people who use services and their carers have been identified in *Talking Points*¹⁶ and are outlined in *Leading for outcomes: a guide* (p14). It is safe to assume that these core values are likely to be shared by all people regardless of whether or not they have a diagnosis of dementia. However, research by Bamford and Bruce (2001)¹⁷ explored the particular outcomes people with dementia said were important to them. These outcomes focused on elements that enhanced quality of life and ways in which services were delivered.

16 Developed by the Joint Improvement Team (2009) available here <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>

17 Bamford C and Bruce E (2001) Defining the outcomes of community care: the perspectives of older people with dementia and their carers, *Ageing and Society*, 20, 543-570

exercise one



defining the approach and promoting the benefits of an outcomes-focused approach in dementia

Learning outcomes

- = understanding what outcomes are and how they differ from outputs
- = recognising outcomes that are important to people with dementia and their carers



Time

Spend at least 45 minutes



Materials

PowerPoint or flipchart paper to display the training materials

Flipchart paper to record key discussion points

Instructions

- > It is important that your team understand the elements of an outcomes-focused approach and how these differ from service outputs. Depending on their level of understanding you may want to take them through exercise 1 in *Leading for outcomes: a guide* (p 11).
- > Once a good understanding has been established, ask your team to brainstorm:
 - outcomes they think might be important to people with dementia
 - outcomes they think might be important to carers of people with dementia
- > Depending on the size of your group you could split them into two or three smaller groups for this exercise.
- > Bring the group(s) back together and introduce the quality of life and service process outcomes listed in the training materials for exercise 1.
- > Ask your team to compare these with those they had identified through the brainstorming exercise. Facilitate a discussion around any similarities or differences between the outcomes identified in the group and those in the training materials.
- > Discuss with your team what they think the benefits are of an outcomes-focused approach in the context of dementia. Record key points on flipchart paper.



exercise one: training materials

“ Outcomes important to people with dementia (Bamford and Bruce, 2001)

‘Quality of life outcomes centre on having access to normal activities and patterns of life in ways that maximize feelings of choice and control and encompass social, physical and emotional needs’.
(p561)

- Access to social contact and company
- Having a sense of social integration
- Access to meaningful activity and stimulation
- Maximising a sense of autonomy
- Maintaining a sense of personal identity
- Feeling safe and secure
- Feeling financially secure
- Being personally clean and comfortable
- Living in a clean and comfortable environment.
(p554)

‘Service-process outcomes are concerned with the desired impacts of service delivery’.
(p561)

- Having a say in services
- Feeling valued and respected
- Being treated as an individual
- Being able to relate to other service users.
(p554)

exercise two



challenges to working in an outcomes-focused way in the context of dementia

Learning outcomes

- = understanding the individual and organisational challenges of an outcomes-focused approach in the field of dementia
- = understanding how challenges and concerns might be addressed to allow your team to move forward with this approach.



Time

Spend about 45 minutes



Materials

Flipchart paper

It is important that your staff have an opportunity to explore what they see as the challenges to working in an outcomes-focused way with people that have dementia and their carers. As a leader, it is important that you help support your staff to address barriers and concerns, as well as encourage them to think about ways to meet these challenges. You may find it useful to run exercise 2: outcomes-focused and service-led compared in *Leading for outcomes: a guide* (p16) with your team.

Instructions

- > Ask your team to work together in groups to identify what they think are the individual and organisational challenges to an outcomes-focused approach in the context of dementia.
- > List these challenges on a flipchart.
- > Next, ask your team to prioritise the challenges – which are the most significant and why?
- > Ask your team to focus on ways they can address these challenges. Ensure staff don't simply focus on an increase in money and resources to address all barriers – what can they do with what they have?

part three

key settings

3

People with dementia live in a variety of settings which can influence how staff work with them to help achieve outcomes.

These can include:

-  Living at home with a carer (who may be a close friend, family member or spouse)
-  Living at home alone
-  Living in supported accommodation (eg sheltered accommodation, extra care housing)
-  Living in a care home (residential or nursing home)

The exercises in this section aim to encourage staff to consider an outcomes-focused approach in these different settings and the outcomes likely to be important to people with dementia and their carers. It is important to point out that in the real world, staff will have conversations with the person with dementia and / or their most reliable proxy, to identify the outcomes important to them. For the purposes of these training exercises, staff need to imagine they have had these conversations through which outcomes have been identified. The 'outcomes conversation' with people with dementia and carers is further explored in section 4 of this guide.

Each exercise follows the same format and provides a framework within which to explore key issues. Again, these exercises are designed to be adapted so wherever possible you could use a real life case study or scenario that staff have encountered.

For the exercises in this section, it may be helpful for staff to refer to the outcomes identified on page 14 of *Leading for outcomes: a guide* and / or the outcomes listed in the training materials for exercise 1 of this guide, as a reminder of the outcomes that are important to people with dementia and their carers.

exercise three



living at home with a carer

Learning outcomes

- = identifying the enablers and barriers to an outcomes-focused approach when a person with dementia is living at home with a carer
- = recognising the possible outcomes for a person with dementia and their carer in this setting
- = thinking about how to address conflicting outcomes
- = exploring the importance of the relationship between the person with dementia and their carer



Time

Spend at least an hour



Materials

Flipchart paper

Print copies of or use a PowerPoint slide to display the scenario

Instructions

- > Introduce the scenario in the training materials for exercise 3 to your team.
- > Ask your group to work through questions 1-4 together.
- > Facilitate a discussion around their answers. Record key points on a flipchart.
- > Ask the group to consider the possible outcomes of Jane and Tom as per the activity.
- > Move on to questions 5, 6 and 7 to explore the complexities of dementia in this setting.



exercise three: training materials



Scenario Jane

Jane is 69 and is in the middle stage of dementia. She lives at home with her husband Tom who is 74. Tom's health has got worse recently. They have been married for 32 years but since Jane's diagnosis three years ago and Tom's health problems, their relationship has become difficult.

- Q1. What would support you to work in an outcomes-focused way in this setting?
- Q2. What would hinder you working in an outcomes-focused way in this setting?
- Q3. How do you think the relationship between Jane and Tom impacts on an outcome-focused approach?
- Q4. How would you help support Jane and Tom to improve their relationship?
- * **Activity: Brainstorm the possible outcomes for Jane and Tom.**
- Q5. Jane and Tom may have conflicting outcomes – how would you address this?
- Q6. Would your answers to the questions in this exercise change if Jane had late-stage dementia? If so, how?
- Q7. What would the key issues be for working in an outcome-focused way if Jane's carer were her married daughter, a mother of two small children?



exercise three: training materials / continued

Further information

- > The relationship between the person with dementia and their carer(s) is key in this setting. The individual and their carer may value support in the development or maintenance of a positive relationship.
- > Being a carer can be a difficult job so it is essential that they are well supported¹⁸. Working with carers to identify their outcomes is discussed in more depth in section 4 of this guide.
- > Maintaining existing social networks and support for as long as possible is crucial for both the person with dementia and their carer.
- > Information about local organisations or services to which people can turn for help may not be known to individual staff, so it is important for your staff to check with Alzheimer Scotland regularly and ask for the current local services guide or download it from www.alzscot.org. If you provide a service or know of any services that have been omitted, please contact Alzheimer Scotland. You can also give the free 24 hour support helpline number (0808 808 3000) to the person with dementia and their carer. It will also help signpost you to a dementia advisor in the area, or a dementia nurse attached to the local hospital.
- > There is a range of written support material and DVDs that you can provide for the person and their carer.¹⁹
- > The literature highlights some helpful responses to issues such as aggression, anxiety and agitation, depression, hallucinations, sleeplessness and ‘wandering’ (where the person becomes lost, or leaves the house, which is also known as ‘purposeful walking’)²⁰. Staff need to be familiar with a range of practical solutions to each of these problems²¹ and be in a position to advise the carer on what they can do.
- > When a person with dementia lives at home with a carer, it is useful for staff to be familiar with issues such as:
 - > What allowances are available to carers?²²
 - > How does a person with dementia access self-directed support?²³
 - > Information about power of attorney²⁴
 - > Information about driving²⁵
 - > Finding a care home²⁶

18 Carer resilience: <http://www.scie.org.uk/publications/windowsofopportunity/personalresources/carerresilience.asp>

19 *Coping with Dementia: a practical guide for carers*, (2009), NHS Health Scotland from Alzheimers Scotland, local health centres or available as a download from www.healthscotland.com/documents/1469.aspx Details of other publications on the NHS Health Scotland website at www.healthscotland.com

20 Hulme C and colleagues (2010), Non-pharmacological approaches for dementia that informal carers might try or access: A systematic review, *International Journal of Geriatric Psychiatry*, 25(7), 756-763

21 *Ten Helpful Hints for Carers: practical solutions for carers living with people with dementia*, Stirling DSDC (2009) (<http://www.dementiashop.co.uk/products/10-helpful-hints-carers-practical-solutions-carers-living-people-dementia>)

22 www.alzscot.org/pages/info/money-and-legal-matters.htm provides guidance on carers allowances

23 Go to www.alzscot.org/pages/info/directpayments.htm for information about self directed support

24 Go to www.alzscot.org/pages/info/money-and-legal-matters.htm for general guidance on powers of attorney

25 Go to www.alzheimers.org.uk for factsheet 439 about driving and the Driving Assessment Service in Scotland

26 www.firststopcareadvice.org.uk for advice from Counsel and Care, a charity



exercise four

living alone at home

Learning outcomes

- = identifying the enablers and barriers to an outcomes-focused approach when a person with dementia is living at home alone
- = recognising the possible outcomes for a person with dementia in this setting
- = understanding how staff's values may conflict with an outcomes-focused approach



Time

Spend about an hour



Materials

Flipchart paper

Print copies of or use a PowerPoint slide to display the scenario

Instructions

- > Introduce your group to the scenario in the training materials for exercise 4.
- > Ask the group to work through questions 1 and 2, then feedback their key points. Again, you can make notes or record on flipchart.
- > Use the brainstorming exercise to get staff thinking about the possible outcomes for Anwar.
- > Ask the group to discuss question 3 and provide feedback.
- > Lead a discussion around the group's answers to question 4. Draw out their experiences of working with people with dementia and their carers where capacity has been an issue. What is their experience of the Adults with Incapacity (Scotland) Act 2000?

exercise four: training materials



Scenario Anwar

Anwar is 81 and lives alone in his own home since his wife died 18 months ago. He is in the middle stage of dementia. Neighbours have contacted social services as they have noticed that Anwar is 'wandering' the street outside his house late at night. One neighbour that has helped Anwar back inside has reported that he is living in 'squalor' and is very concerned about the state of his home. Anwar insists he wants to remain in his own home and can take care of himself.

- Q1. What would support you to work in an outcomes-focused way in this setting?
- Q2. What would hinder you working in an outcomes-focused way in this setting?
- * **Activity: Brainstorm the possible outcomes for Anwar.**
- Q3. How might staff approach situations where their values are in conflict with the outcomes identified by the person with dementia?
For example, who decides what constitutes 'squalor'?
- Q4. Consider how your answers might change if:
- Anwar has capacity
 - Anwar lacks capacity



exercise four: training materials / continued

Further information

- > Social isolation is a significant risk for people living alone. Social networks can be a protective factor to ill health so staff need to think of ways to help support the development or maintenance of social networks²⁷.
- > Much like the person who lives at home with a carer, the role of home care workers is crucial. Their understanding of dementia and issues such as maintenance of privacy and dignity will be essential to the provision of appropriate services. Assessing their awareness with tools such as the Home Care Practice License (HCPL)²⁸ offers assurance about how these unsupervised workers are coping with the challenges presented by people with dementia. It is a test process to validate home care worker competence. It provides a baseline of values, attitudes, knowledge and skills from which domiciliary care workers can progress to specific units from the National Occupational Units.

The HCPL test is appropriate for both experienced and inexperienced care workers. It determines the effectiveness of induction training, identifies skills gaps and training needs. This will assist with staff training plans and provides tangible evidence to demonstrate your commitment to staff development. The test model uses a theory test, a practice observation and oral questions. The materials to assess knowledge and understanding draw on the Scottish Executive National Care Standards for Care At Home and are compatible with the revised National Occupational Standards for Care.

This film developed by SCIE looks at providing care at home for people dementia:
<http://www.scie.org.uk/socialcare/v/video-player.asp?guid=a8d96953-27b5-4d78-a837-e3143533b0d5>

²⁷ Building social capital: <http://www.scie.org.uk/publications/windowsofopportunity/interventions/buildingsocialcapital.asp>
²⁸ www.dementia.stir.ac.uk for more information about home care worker support

exercise five



living in supported care

Learning outcomes

- = identifying the enablers and barriers to an outcomes-focused approach when a person with dementia is living in supported care
- = recognising the possible outcomes for a person with dementia in this setting



Time

Spend about an hour



Materials

Flipchart paper

Print copies of or use a PowerPoint slide to display the scenario

Instructions

- > Introduce your group to the scenario in the training materials for exercise 5.
- > Ask the group to work through questions 1 and 2, then feedback their key points.
- > Use the brainstorming exercise to get staff thinking about the possible outcomes for Rose.
- > Ask the group to discuss question 3 and feedback.



exercise five: training materials



Scenario Rose

Rose is 63 and in the early stage of dementia. She has recently moved into St John's Court, a complex which provides 12 self-contained dwellings and communal facilities within a secure environment. Rose lives in a one-bedroom ground floor flat in the complex. Before moving to St John's Court three months ago, Rose lived alone but after her home was burgled, she became increasingly frightened and socially isolated. Rose is struggling to make new friends and rarely leaves her flat.

- Q1. What would support you to work in an outcomes-focused way in this setting?
- Q2. What would hinder you working in an outcomes-focused way in this setting?
- * Activity: Brainstorm the possible outcomes for Rose.
- Q3. How would you support Rose to increase her social activity and to build relationships?



exercise five:
training materials
/ continued

Further information

- > The important outcomes for people living in supported accommodation are likely feeling safe and maintaining their independence.

“There is mounting evidence that people with dementia living in Extra Care Housing generally have a good quality of life, although studies consistently show that some tenants with dementia can be at risk of loneliness, social isolation and discrimination.”²⁹ (p3)

- > There is strong evidence that important aspects that contribute to quality of life for people with dementia living in extra care settings are:

- maximisation of dignity and independence
- individualised activities and experiences that bring pleasure and a sense of accomplishment (there is some evidence that this may even delay functional decline)
- effective communication
- meaningful social interactions³⁰
- ability to maintain meaningful relationships
- person-centred care
- freedom from pain and discomfort
- the ability to age in place
- the appropriateness, layout and appearance of the physical environment
- access to health care and palliative care when needed.(p5)

29 Dutton R (2009) *Extra Care Housing and People with Dementia: Summary of findings from a scoping review of the literature 1998-2008*, on behalf of the Housing and Dementia Research Consortium with funding from Joseph Rowntree Foundation.

30 Building social capital: <http://www.scie.org.uk/publications/windowsofopportunity/interventions/buildingsocialcapital.asp>

exercise six



living in a care home

Learning outcomes

- = identifying the enablers and barriers to an outcomes-focused approach when a person with dementia is living in a care home
- = recognising the possible outcomes for a person with dementia in this setting



Time

Spend about an hour



Materials

Flipchart paper

Print copies of or use a PowerPoint slide to display the scenario

Instructions

- > Introduce your group to the scenario in the training materials for exercise 6.
- > Ask the group to work through questions 1 and 2, then feedback their key points.
- > Use the brainstorming exercise to get staff thinking about the possible outcomes for Mai.
- > Ask the group to discuss question 3 and feedback.

exercise six: training materials



Scenario Mai

Mai is 91, has late stage dementia and has recently moved into a residential care home. She seems disoriented and loses her way around the home frequently, often ending up in the wrong room which other residents find upsetting. Mai seems increasingly unhappy, confused and spends much of the time sitting in her room alone.

Q1. What would support you to work in an outcomes-focused way in this setting?

Q2. What would hinder you working in an outcomes-focused way in this setting?

* Activity: Brainstorm the possible outcomes for Mai.

Q3. How can staff help ensure a personalised approach in an institutional setting?

exercise six: training materials / continued



Further information

- > The majority of people with dementia live in the community. The majority of residents in care homes, however, do have dementia.
- > The key outcomes for a person with dementia living in a care home may focus on having things to do and keeping well. It may also be very important for them to maintain a life outside the care home. Active involvement in the community, as well as in the care home can help maintain social support networks.
- > Maintaining the identity of the person with dementia is important. Staff who know the personal history, likes, dislikes and values of the person with dementia will be able to better support them (see section 4.1 of this guide for more on this).
- > A crucial aspect of providing support in a way that focuses on individual outcomes is staff attitudes and cultures. Available resources, design of the home and resident mix are important, but staff culture can undermine any positive effects of these. The culture is revealed in how staff speak and listen to residents, how they undertake essential tasks and how they allocate 'discretionary time' ie what they do if they have time to spare between essential tasks.
- > The first and essential need is knowledge of dementia and how to care properly for people affected by it in an institutional setting. There are many short courses on awareness of dementia, but it is vital not to assume that this provides complete dementia awareness. It is important to choose a development programme which supports staff knowledge over time, allowing them to examine their own values and work out how to use them in their work.
- > Care homes for people with dementia should have a 'domestic' or home-like feel to them. Residents' rooms need to be ensuite, incorporating dementia-friendly design principles, including lighting, layout and noise management. Doors should be easily distinguished to prevent accidental intrusion in another person's space, and staff need to respect private spaces by knocking and waiting before entering. Residents need access to outside places and easy access to toilets. Continence can be significantly affected by design and routines. There are many sources of detailed guidance on toilets and bathrooms.³¹
- > Common areas should not be traffic routes for supplies and laundry and residents need to see and smell food preparation to encourage good appetite. Care homes should aim to have a dementia design audit certificate.³²

³¹ www.scie.org.uk/publications/dementia/environment/toilets.asp provides detailed guidance on toilets and dementia.

³² A self assessment checklist is available free from www.dementiashop.co.uk



exercise six:
training materials
/ continued

- > Design of routines helps as well as physical design. It helps if you are flexible about where a person eats and when, and times for getting up and going to bed, and where they are allowed to sit, or to walk around inside and outside.
- > People in care homes are often on more medication than necessary, so regular reviews from the GP or pharmacist are important. 'Disturbing' or 'challenging' behaviour is commonly caused by undiagnosed pain so ensure the person with dementia has regular reviews with a GP. Medication can be seen as a form of restraint and Mental Welfare Commission guidance should be followed on this and other restraint issues.³³
- > Exercise and activities, particularly in the open air, are crucial for health. Exposure to day light helps set the body clock and exercise has a strong evidence base for improving sleep, anxiety, diet, constipation and reduction in falls.
- > Behaviours involving aggression, wandering / purposeful walking, sleeplessness, sexual disinhibition, apathy, repetitive vocalisation are common in people with dementia, and managing the risks presented by it are crucial³⁴ Staff need to be educated on this and the ethical and legal issues associated with their responses.³⁵

33 *Rights, Risks and Limits to Freedom; principles and good practice guidance for practitioners considering restraint in residential care settings*, Mental Welfare Commission, Edinburgh, 2006

34 See SCIE's resources on difficult situations: <http://www.scie.org.uk/publications/dementia/difficult/index.asp>

35 Contact www.dementia.stir.ac for details of the Best Practice Programme, which trains facilitators to educate care home, home care and day care workers in their own teams on these issues using accredited materials

part four identifying outcomes

4

In order to identify outcomes, effective communication is essential. At this point it will be helpful for your team to read pages 24 and 25 of *Leading for outcomes: a guide* which introduces the idea of the ‘outcomes conversation’ through which staff work with people who receive support to identify outcomes. It will also be beneficial to direct your team to ‘Good conversations: Assessment and planning as the building blocks of an outcomes approach’ developed by JIT (2011) which provides examples of outcomes focused conversations³⁶.

This section will look at effectively communicating with people with dementia and their carers to identify, negotiate and set outcomes. Key to an outcomes-focused approach is to build the resilience of people with dementia and their carers and to harness their personal resources³⁷.

36 Freely available here: <http://www.jitScotland.org.uk/downloads/1303213515-outcomes%20focused%20conversations.pdf>

37 Personal resources: <http://www.scie.org.uk/publications/windowsofopportunity/personalresources/index.asp>

4.1

the outcomes conversation with people with dementia

Dementia can pose challenges to the outcomes conversation especially if there are communication impairments where the person with dementia has difficulty using or understanding language. When this happens, the interpretation of non-verbal communication and observation skills become even more important. It is important to remember that all behaviour in dementia is communication, so staff will need to try harder to work out what is being 'said'. The outcomes conversation relies heavily on staff's capability to ask the right questions and to be an active listener.

An insight into the person with dementia's personal background can help to understand them and what they are trying to communicate. Using an alternative communication tool such as Talking Mats³⁸ can help for those with communication impairments. Talking Mats use symbols on a textured mat for people to indicate their views about various options within a topic. These tools can be used between staff and a person with dementia or between a person with dementia and their carer. Research has found that 'people with dementia and their family carers both feel more involved in discussions when using Talking Mats, compared to their usual communication methods. They also feel more satisfied with the outcomes of these discussions'.³⁹

38 www.talkingmats.com

39 *Talking Mats help involve people with dementia and their carers in decision-making*, Joseph Rowntree Foundation, 2010 available here: <http://www.jrf.org.uk/publications/talking-mats-decision-making>

4.1 the outcomes conversation with people with dementia / continued

Memory boxes, reminiscence therapy and life story work

Memory boxes can be used to support positive interactions between people with dementia, their carers and staff. They can be filled with photographs, memorabilia and any other items that have personal significance to the person with dementia. Memory boxes, life story work and reminiscence therapy can help support the person with dementia to maintain their identity.

- > Reminiscence therapy and in particular life story work provide a context for the provision of person-centred care, whether in the home, nursing home or hospital context.
- > Life story work can be especially valuable when the person with dementia is transferred from a home to an institutional setting, or between institutions⁴⁰.

- > Reminiscence therapy and life story work can improve the mood, cognitive ability and well-being of those with mild to moderate dementia. Research suggests that the effects of biographical interventions are weaker for people with severe dementia.
- > There is evidence to support the view that life story work can improve the relationship, whether family or professional, between the person with dementia and their carer(s).

40 Taken from *Supporting those with dementia: reminiscence therapy and life story work*, IRISS Insights, 2010 available at: <http://lx.iriss.org.uk/collections/IRISS%20Insights>

exercise seven



communication

Learning outcomes

- = reflecting on non-verbal behaviour as a means of communicating
- = identifying effective ways to communicate with people with dementia



Time

Spend about an hour



Materials

Flipchart paper

Print copies of or use a PowerPoint slide to display the scenario

Instructions

- > Introduce your staff to the scenario in the training materials for exercise 7. You can use a real life example or scenario if you or your staff have one.
- > Depending on the size of the group, split into smaller groups to work through the questions.
- > Bring the groups back together and facilitate a discussion around their answers. Draw out what experiences staff have had with any of these issues.
- > Based on the feedback from question 6, devise with your group a checklist of key points for effective communication with people with dementia.



exercise seven: training materials



Scenario Meave

Meave Pitchford, who has dementia, is in her bed in her care home, lying still and sighing from time to time. Staff have decided that it is time for her to get up, because she probably needs the toilet and it is good for her to have exercise. In any case it is nearly time to eat. Although her limbs are quite contracted, she thrashes about when they start to move her and she shrieks and groans. They decide to whisk her out of bed as quickly as possible to minimise the disturbance, and quickly get her sat up on a commode. She continues to dribble and groan, and when someone comes near her to ask what she wants for breakfast she bellows and shouts unintelligibly. Later, she spits out all the food that is spooned into her mouth.

- Q1. In what ways is Meave communicating?
- Q2. Describe what these types of behaviours might indicate.
- Q3. In this situation, what might staff do differently?
- Q4. Could spitting out food indicate any other problems?
- Q5. What might staff do differently if they knew that Meave has sensory impairments?



exercise seven:
training materials
/ continued



Q6. Think about how you currently communicate with people with dementia - what have you found works well?

Q7. Carers and family members are often relied upon to fill in the personal background of people with dementia. What alternative ways can you think of to find out about a person with dementia in the absence of information from carers?

Further information

- > JIT have developed *Improving communication around outcomes: a resource to support reflection and practice development*⁴¹ as part of the *Talking Points* resources which will be useful to your staff.
- > The Social Care Institute for Excellence (SCIE) have a range of free learning materials in the *Dementia Gateway*⁴², particularly useful for this exercise is 'Getting to know the person with dementia' which includes tools to help support communication.

41 Available on the JIT website: <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/communication-skills/>
42 <http://www.scie.org.uk/publications/dementia/index.asp>

4.2

the outcomes conversation with carers of people with dementia

Carers are the biggest source of care and support in each area of the UK. Carers play a vital role in supporting people with dementia to achieve their outcomes and to remain in their own homes longer. However, being a carer can be a difficult job and can have a profound impact.

It is equally important to have an outcomes conversation with the carer of the person with dementia to ensure they too have an opportunity to identify the outcomes important to them. Although they are entitled to a carer's assessment, staff need to ensure outcomes are addressed as part of this process.

- > Taking on a caring role can mean facing a life of poverty, isolation, frustration, ill health and depression.
- > Many carers give up an income, future employment prospects and pension rights to become a carer.
- > Many carers also work outside the home and are trying to juggle jobs with their responsibilities as carers.
- > The majority of carers struggle alone and do not know that help is available to them.
- > Carers say that access to information, financial support and breaks in caring are vital in helping them manage the impact of caring on their lives⁴³.

43 Taken from the Princess Royal Trust for Carers: (<http://www.carers.org/why-do-carers-need-support>)

4.2

the outcomes conversation with carers of people with dementia / continued

Voices of Carers Across Lothian (VOCAL) are an example of an organisation that has an outcomes-focused approach to supporting carers. VOCAL identify six outcomes (adapted from carer outcomes outlined in Talking Points) which it seeks to achieve with unpaid carers:

1. Carers will feel better informed about issues linked to their caring role
2. Carers will have increased self-esteem and increased confidence in managing their caring role.
3. The physical and mental well-being of carers will be improved.
4. Carers will be more confident in their ability to deal with the changing relationships resulting from the caring role.
5. Carers will be more confident in their ability to shape the services and support available to them.
6. Carers will be more confident in their ability to combine caring responsibilities with work, social and learning opportunities.

To capture these outcomes, VOCAL developed the Carer Outcomes Tool (COT). The tool enables a flexible approach to having the outcomes conversation and can be conducted over the phone, or face to face over one or several meetings. Staff work with the carer to identify outcomes. The carer rates these as 'very important', 'important', 'small issue' or 'not an issue'. A review of progress is then undertaken within six months whereby the carer is asked to rate the change they have experienced in terms of 'big improvement', 'small improvement', 'no improvement' or 'worse'.⁴⁴

44 For more on the COT contact VOCAL: <http://www.vocal.org.uk/>

4.3 setting outcomes – negotiation and risk enablement

Identifying the outcomes important to people with dementia and their carers may call for some negotiation to set achievable and appropriate goals. Fear, denial, lack of insight and / or disagreements between the person with dementia and their carer(s) can affect the setting of outcomes. Staff also need to consider risk as well as legal and ethical frameworks when setting outcomes. 'Risk enablement' describes an approach where people with dementia are supported to take risks⁴⁵. The ethos of risk enablement helps support an outcomes-focused approach and to help people with dementia remain independent and empowered for as long as possible⁴⁶.

45 See *Nothing Ventured, Nothing Gained*, Department of Health, 2010 for more information: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

46 See also JIT's resources on Risk, Outcomes and Safeguarding: <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/risk-outcomes-and-safeguarding/>

exercise eight



setting outcomes

Learning outcomes

- = understanding the role of staff in helping identify appropriate outcomes
- = understanding the challenges to setting outcomes
- = identifying ways to address these challenges



Time

Spend at least 40 minutes



Materials

Flipchart paper

Instructions

- > Ask your team to work in groups of two or three to discuss the situations described in the training materials for this exercise and how they might address these. Again, where possible discuss real life examples.
- > Bring the small groups together and lead a discussion around their feedback. Record key points on a flipchart.
- > Encourage your team to discuss the skills and techniques they think help to set outcomes when issues of fear, denial or lack of insight occur. Consolidate these into a checklist or list of good practice recommendations.



exercise eight: training materials

How would you address the following situations to help ensure the setting of appropriate and achievable outcomes?

- A person with dementia has identified two key outcomes they want to work towards. They live with a carer but their carer disagrees that these outcomes will improve the person's quality of life.
- A carer has identified an outcome they want to achieve but you are worried that the outcome might undermine their ability to care for the person with dementia.
- A person with dementia has identified an outcome but you feel it's not achievable or appropriate given their stage of dementia and capability.
- A person with dementia is in denial about their condition and will not acknowledge the impact it is having on their ability to deal with financial matters such as paying bills and rent.
- A carer is insisting that they want to continue caring for their spouse who has dementia at home, but you are concerned that the carer is unable to provide an adequate level of care.

exercise nine



risk enablement

Learning outcomes

- = understanding key risks for people with dementia and their carers
- = understanding risk enablement in the context of dementia
- = identifying risks and considering the potential impacts



Time

Spend at least an hour



Materials

Flipchart paper

Print copies of Table 1, Table 2 and the scenarios

Instructions

- > Lead a group discussion around Question 1.
- > After the group have had a chance to explore what they think the key risks are, introduce those outlined in Table 1.
- > Compare risks identified by the group and those in Table 1. Are they similar or different? Discuss.
- > Move on to Activity 1. This can be done in small groups or in the large group led by you. This activity is to encourage staff to recognise the difference ways in which risk is perceived in an outcomes-focused approach compared to a service-led approach.
- > Ask your team to work in small groups on Activity 2 to identify the risks for Alan, Jamilla, Malik and Kate. Substitute these for real life examples or scenarios where possible.
- > Bring the small groups back together to discuss the risks they identified and the impact of each.
- > Highlight to the group that identification of risk, impact, likelihood and severity are key evaluation criteria to help draw up risk enablement plans in collaboration with people with dementia and their carers.



exercise nine: training materials

Q1. What do you think are the key risks for people with dementia and their carers?

Table 1:
Key risks facing people with dementia and their supporters⁴⁷

1. At the time of diagnosis of the dementia or realisation of what it means

this may be a very emotionally disruptive time, 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 a while if they can.

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 a risk might be helpful.

3. When there is a decline in physical or mental health

again, this might be leading 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 or sight may affect people's ability to manage some risks.

***** Activity 1: Brainstorm what you think are the key differences between how risk is perceived in an outcomes-focused approach and in a service-led approach.

***** Activity 2: Fill in Table 2 for each of the scenarios on page 40.

⁴⁷ Taken from *Nothing Ventured, Nothing Gained: Risk Guidance for people with dementia*, Department of Health, 2010, p 8



exercise nine:
training materials
/ continued



Alan

Alan is 72 and is in the middle stage of dementia. He has recently been bereaved from his wife, and has no children. Alan used to have his own plastering business locally and before his diagnosis had a lot of friends and networks – not so much recently as he finds it more and more difficult to be understood and to understand what people are saying. He has always thought of himself as a ‘handy’ man and is continuing to attempt to fix and mend things around his house. He has recently injured himself for the second time. He lives at home alone.



Jamilla

Jamilla was diagnosed with early-onset dementia at the age of 49. She has always loved the countryside and lives at home with her husband in a remote part of Scotland – using the car to travel to visit friends and family. Jamilla has always loved hill walking and used to spend hours trekking through the hills nearby. Because she has been disorientated and confused recently, her husband has taken to discouraging her from going walking and refuses to let her drive. This has caused some tension in their relationship, and Jamilla has lost interest in undertaking other activities. Her family are concerned she has become quite depressed. Jamilla has also begun to make accusations that her husband is withholding money from her.



Kate

Kate is 79 and has late stage dementia. She lives in the home that she has owned for 20 years. Her son, daughter in law and young family have recently moved in to help care for her. Kate’s memory is failing and she is often confused and disorientated. These problems often cause Kate to neglect herself and frequently leave home and get lost. One of the issues that makes her particularly vulnerable is her tendency to talk to complete strangers and to tell them details about where she lives and when she will and won’t be home. She rarely sleeps at night and often wanders the house for hours, which tends to wake the children.



Malik

Malik is 82 years old and had a bad fall recently. Since moving from the hospital into a care home he has experienced increased problems with his dementia. His confusion and memory problems have been even more pronounced – he appears to be in a chronic confused state. Malik is angry and confused and doesn’t understand why he is not at home with his wife. Prior to his retirement, Malik was a chef, and had a great love of food and cooking. Even though he finds it difficult to follow recipes, he is frustrated that he does not have access to the kitchen facilities. He is suspicious of the other residents and has begun to hoard food and other items in his room.



exercise nine:
training materials
/ continued

Table 2:
Identifying risks and impacts⁴⁸

Risk area	What would be the impact if harm happened?	How likely? High, Medium, Low	How severe? High, Medium, Low
Alan:			
Jamilla:			
Kate:			
Malik:			

⁴⁸ Taken from *Nothing Ventured, Nothing Gained: Risk Guidance for people with dementia*, Department of Health, 2010, p 9

part five planning for action

5

After identifying outcomes the next step is to consider how these can be achieved. It is important to develop support plans that are not service-led. In this section, encourage your team to consider innovative ways of achieving outcomes, involving social and community networks or services available in the community.



exercise ten

brainstorming for solutions

Learning outcomes

- = developing innovative solutions to achieving outcomes
- = addressing barriers to solutions



Time

Spend about an hour



Materials

Print copies of the scenarios

Instructions

- > Ideally divide into smaller groups. Each group should be allocated a scenario from the training materials for this exercise and asked to think of at least one specific outcome that could be worked towards for that scenario.
- > The group should then consider the typical way that they might go about achieving the outcome and then to come up with as many alternative ways as they possibly can. Explain at this stage that staff shouldn't put too much emphasis on constraints due to resources. Encourage as many ideas as possible.
- > Also encourage the group to think about how they would involve the person with dementia and their carer(s) in developing solutions.
- > Ask each group to choose their two best solutions to each scenario.
- > Within the small groups, discuss each solution in more depth for a few minutes. For each solution ask the group to come up with:
 - Reasons why the solution is effective.
 - Resources that would be required to implement the solution.
 - Any partners that would need to be involved to implement the solution. This could include other agencies or services but also families and friends.
 - Barriers to implementing the proposed solution.
 - How, if at all, the barriers could be overcome.
- > Bring the small groups back together and discuss the solutions proposed.

exercise ten: training materials



Scenario 1: John and Elsie

John has dementia and lives in a care home. Staff recently observed that he has become over familiar with the female residents. One evening he is found in bed with Elsie who appears to think he is her husband. She is a widow⁴⁹.



Scenario 2: Annie

Neighbours complain that Annie is frequently in the street in her dressing gown and slippers in the early hours of the morning, in all weathers. They call social services to say she should be taken into care. Her daughter in Canada agrees.



Scenario 3: David's daughter

David has late stage dementia and lives in a care home. David's daughter Jean, who used to be his carer, is very demanding and frequently visits the home with complaints. This is causing tension between staff at the home and Jean, as well as between David and the staff.



Scenario 4: Namira

Namira is in the middle stage of dementia. She has been taken into hospital after a fall and is described as having disturbing behaviour. None of the independent sector care homes in your area are prepared to accept her.

49 Dementia and sex: the last taboo available here:
<http://www.communitycare.co.uk/Articles/2011/03/23/116495/dementia-and-sex-the-last-taboo.htm>

part six

reflecting on progress

6

A service-led approach tends to measure progress or success in terms of outputs, such as the number of people who received a service, or how long it took to carry out an assessment. Such measures tell us little about how people are enabled to achieve what is important to them and they fail to address the key issue of what difference support makes to the lives of those receiving it. In contrast, an outcomes-focused approach seeks to measure the impact support has made and takes personal goals as a legitimate measure of progress.

Exercise 7 in *Leading for outcomes: a guide* (p35) outlines an approach for measuring change within an outcomes-focused approach and you may find it beneficial to cover this with your team.

exercise eleven



measuring progress – what are the challenges?

Learning outcomes

- = reflecting on how staff currently measure progress and improvements
- = recognising the challenges of measuring progress in an outcomes-focused approach in the context of dementia
- = exploring possible ways to address these challenges



Time

Spend about 30 minutes



Materials

Flipchart paper

Instructions

- > Ask the group to consider question 1.
- > Use their feedback to compile a list of key points for addressing the challenges they identify.
- > Use the points in the further information section to flesh out the discussion if necessary.
- > Lead a discussion with the group about their current methods of measuring progress. How could these methods be improved or adapted to make them more outcome-focused?



exercise eleven: training materials

Question 1.

- What challenges does dementia pose for measuring outcomes?
- How might you address these?

Question 2.

- How do you currently measure progress and improvement for people with dementia?
- How can you ensure this process is more outcomes-focused?

Further information

- > Dementia is progressive and therefore regular reviews should be undertaken to ensure the outcomes that have been identified remain current and that risks have not increased.
- > Lack of insight, memory problems, communication impairment and issues around capacity can make measuring progress more challenging.
- > Where necessary, staff should talk to carers of the person with dementia and other agencies that have contact, to help inform progress made towards particular outcomes.
- > Alternative communication tools (eg Talking Mats) could be used to find out how people with dementia feel about progress and improvements.
- > For carers, VOCAL's Carer Outcomes Tool provides a framework for reviewing the progress towards achieving outcomes whereby carers rate the level of improvement they feel about previously identified issues. A similar framework could also work for people with dementia depending on their capacity and insight.
- > JIT also have some sample recording and measurement tools available here: <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/sample-tools/>

**Institute for Research and
Innovation in Social Services**

**Brunswick House
51 Wilson Street
Glasgow G1 1UZ**

T: 0141 559 5059

www.iriss.org.uk

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