Management and Outcomes for people with ID and dementia

Dr Karen Dodd
Associate Director, Specialist Therapies – Learning Disabilities / Consultant Clinical Psychologist

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Dementia and People with ID

» Much of the focus is on assessment and diagnosis and following the course of the disease.

» Much less focus in the literature on the management for the person, and their supporters to ensure quality outcomes.

» Today – will focus on what are the elements of good management for people with ID and dementia and how to measure that this is being achieved.
Management of people with ID and dementia

Need to consider:

- Staff training and support
- Support for individual
- Support for peers
- Support for families
- Working with care managers and the wider system
Staff training and support

- Whole system
- Changing condition
- Giving staff an understanding of what it feels like to the person
- Philosophy of care
- Reality orientation v validation
- Environments
- End of Life Care
McCarron (1999) identified the requisites of good care for people with ID and dementia.

- Importance of developing a shared vision on which to build practice.
- Without this solid foundation, values, expectations and approaches are likely to differ greatly amongst staff.
- This will ultimately generate conflict and frustration.
- This will place unnecessary demands on an already confused person.
## Changing Condition

<table>
<thead>
<tr>
<th></th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
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<tbody>
<tr>
<td>Memory</td>
<td>Can’t remember what happened yesterday, or even five minutes before but early life preserved</td>
<td>Even early life memories start to deteriorate.</td>
<td>Memories from early life may be randomly triggered</td>
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<tr>
<td>Language</td>
<td>Difficulties finding the correct word</td>
<td>Difficult to speak to you and understanding what you are saying</td>
<td>Limited or no language and little understanding of what is being said to them</td>
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<tr>
<td>Perception</td>
<td>Misplacing objects</td>
<td>Getting lost in familiar surrounds</td>
<td>Unable to find their way around</td>
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<td></td>
<td>Difficulty judging steps and stairs</td>
<td>Falling due to misperceiving distances</td>
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<tr>
<td>Executive function</td>
<td>Changes in personality and behaviour e.g. become less motivated</td>
<td>Difficulty staying alert during the day</td>
<td>Difficult to undertake any part of basic tasks such as washing, dressing, toileting</td>
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<td></td>
<td>Difficulty with everyday tasks such as making tea</td>
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Understanding of dementia

Buijssen (2005) described a model of care for people with Alzheimer’s disease in the general population.

Proposes two laws of dementia, and asserts that by understanding them, and their consequences, this gives a framework to understand and respond to people appropriately.

**Law of Disturbed Encoding:** The person is no longer able to successfully transfer information from their short term memory and store it in their long term memory. This basically means that the person is unlikely to remember things that have just happened to them.

**Law of Roll Back Memory:** At first long term memories will remain intact, however as dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether. Deterioration begins with the most recent memories and progresses until only memories of early childhood remain, hence memory can be said to be ‘rolling back’.

For a better life
Philosophy of Care

Excellence in dementia care requires staff and family carers to:

- understand and know the person.
- understand dementia and its consequences for the person.
- and to consequently be able to think ahead and predict ‘stressors’.
- They need to adapt their approach to ensure that the person with dementia has:
  - stress free
  - failure free
  - individualised care
  - that is consistent
  - without time pressures.
- needs to be incorporated into the person’s person centred plan.

For a better life
Be clear about what needs to be achieved

- not the time for learning new skills, achieving goals or facing change.
- consider the person’s happiness, comfort, and security.
- the focus of care should move away from targets to quality of life.
- People compensate for their deterioration in functioning by making greater use of remaining abilities e.g. earlier memories.
- Roll back memory may also mean that the person is not oriented to the present day. Care needs to be taken not to routinely challenge the person’s beliefs as this will add to their stress.
- Need an increasing awareness of the physical consequences of getting older and additionally having dementia.
- Ensure that diagnostic overshadowing does not occur.
- Pain recognition and management is often extremely inadequate.
Reality orientation means finding ways to orientate people to reality.

In early stage dementia, reality orientation clearly has its place when people are ‘nearly oriented’.

The use of cues, gentle reminders, photos and pictures can help the person to engage with the world around them, but this must be achieved in a meaningful and stress-free manner.

As the dementia progresses, the person with dementia does not remember events that have happened in the past as their memory ‘rolls back’ to an earlier time.

This frequently results in the person asking for people who either are no longer alive, or part of their lives.

This is where the controversy exists.

If they can’t enter our world, we must enter theirs and affirm it. Forget reality orientation – Enjoy fantastic adventures with them in their ‘real’ world instead. Be prepared to time travel backwards into their personal history – Barbara Pointon.
Dementia friendly environments

Most environments where people with ID live are not dementia enabled.

Adaptations will need to be made to ensure that the environment does not add more stress to the person with dementia. Many of the adaptations required are not too expensive but can have a very positive effect on the quality of life for the person with dementia.

Environments may need to be altered to be:

- **Calm** – noise (internal and external), colour
- **Predictable and making sense** – cues, signposting, no surprises
- **Familiar** – homely, long term memory
- **Suitably stimulating** – noise, views
- **Safe and risk assessed** – access, stairs, hazards

For a better life
For a better life
End of Life - Dying in place

- Recognising that dementia is a terminal illness.
- Advanced planning – links to Care management and environments.
- Links to palliative care services.
- Training and information.
- Confidence of staff.
- Emotional support and training for staff /carers.
- Additional staff as required including waking night staff.
- Place of death.

For a better life
Support for individual

Aim: To promote wellbeing, reduce anxiety and confusion, keep engaged, promote good health

- Supporting documents
- Life Story work
- Reminiscence
- Activities and Interventions
- Prompts
- Health monitoring and intervention
- Behaviour

For a better life
Supporting documents

- Person Centred Plan
- Health Action Plan
- Communication Passport
- Capacity / Best Interests
- Care Plan
- This is Me – My Care Passport
Life Story Work

Kerr & Wilkinson (2005) said of people with dementia that ‘if you do not know their past then you cannot understand their present’

- Helps to maintain people’s sense of self esteem and identity by focussing on the things that the person did, that they were good at and enjoyed.
- The process of talking to people about their memories, collecting objects and pictures are the important aspects, as much as the final end product.
- Engaging family members and friends in remembering and producing memories, anecdotes, photos and possessions for the life story is a key and beneficial aspect of the work.
- Use regularly to help reduce anxiety and give the person and staff a sense of the person and who they are rather than focussing on the dementia.
- The Life Story can help staff to understand what the person is referring to when they remember things from their ‘rollback memory’, and this helps them to respond more sensitively. For the person with a ID, a lifestory book would remind any new carers that behind the debilitating illness is a person who enjoyed certain things in life.

For a better life
Reminiscence

- Staff and carers need to remember that people compensate for their deterioration in functioning by making greater use of remaining abilities (e.g. earlier memories).
- This may mean that the person finds comfort in activities and objects from their childhood.
- Reminiscence work can help the person with ID and dementia to find anchors with their past and to help steady and engage the person.
- Reminiscence Therapy is one of the most popular psychosocial interventions in dementia care with the general population, and is highly rated by staff and participants.
- There is less written about its use with people with ID but anecdotally has become valuable in its use with people with learning disabilities and dementia.
Activities and Interventions

- Taking part in occupations (self-care, productivity and leisure) define who we are and provide meaning and pace to our lives.
- The need to engage in activities that have purpose and meaning to us as individuals, is a basic human ‘drive’ that does not diminish or disappear as we age.

Early stage
- Support the person to engage in activities to the best of their ability for as long as possible.

Mid stage
- Adapt an activity/task e.g. breaking activities down into steps.

Late Stage
- Process of engaging in an activity becomes more important than the end product. If the activity has a clear impact upon the wellbeing of the person, it is meaningful and therapeutic to them.
Sensory stimulation (including Snoezelen);
Aromatherapy;
Music and art therapy;
Hydrotherapy;
Support for people to engage in activities; Other failure free activities e.g. looking at magazines, carers sitting with the person describing what is happening.
Anxiety Management;
Relaxation techniques;
Promotion of positive behaviour and feelings of self esteem;
Use of community resources.

For a better life
Prompts and Cues

» Verbal

» Visual
Health monitoring and intervention

- **Annual Health checks**

- **Mobility** e.g. Strategies to maintain mobility, promote exercise, address posture especially regarding respiratory function, correct gait and reduce the risk of falls; Consider equipment needed and promote safe manual handling; Control of pain and discomfort; Pressure area care; Treatment of any difficulties of motor function, adaptation and teaching of skills to include compensatory techniques.

- **Eating/Drinking** e.g. Weight, strategies for maintenance of adequate oral intake in a safe manner; Swallowing assessments, eating programme with dietetic advice and advice regarding posture; Diet to reduce risk of constipation; Dysphagia management.

- **Continence** e.g. Aids/adaptations; Help to maintain continence.
- Epilepsy
- **Pain** – pain signals, pain medication, other interventions
- **Infections** e.g. chest, UTI
- **Diagnostic overshadowing** – e.g. Chron’s disease
- **Medication**
Behaviour

Physical Health

Social Environment

Mental Health

Physical Environment

Get to know the person

For a better life
Support for peers

The effect on other people with ID of seeing a friend deteriorate is rarely considered by services.

Helping peers to understand dementia can reduce their distress and help them to be more considerate and understanding of the changes occurring with the person with dementia, in some cases helping to prevent placements breaking down.

Forbat and Wilkinson (2008) held an advisory forum with eight people with ID attending every two months. Concerns were raised by the people with ID about the impact of living with others with dementia.

The members of the group recognised that people with dementia needed 1–1 time but saw it as having a negative effect on people without dementia.

They also felt that people with dementia as getting special privileges e.g. the person with dementia being offered a quiet space to eat their meal.
There are two main approaches to interventions with peers.

- **Use of resources e.g.**

- **Running short courses for people with ID living with someone with dementia e.g. Lyngaard & Alexander (2004) and Dodd (2008).**

- **Both studies used a variety of visual aids, equipment, role plays and exercises to help residents understand the changes in their friends with dementia. They both showed how a relatively short intervention can result in positive changes for both the people with ID and dementia and their peers.**

For a better life
Support for families

- Co-dependency
- Engagement issues
- Life story work
- Short breaks
- Knowing when to ask for help
Working with care managers and the wider system

- Having a named care manager.
- Regular care reviews.
- Access to flexible funding to meet changing needs without delay.
- Outcomes monitored regarding their quality of life.
- Staffing levels increased as needed including waking night staff.
- Issues re moves and what sort of service.
- No multiple moves.
- Interface with generic primary and secondary care.
Measuring Outcomes

- Some tools have been adapted to look at specific issues e.g. carer burden, behaviour.
- Joint guidance gives recommendations re good practice.
- Some services using general outcome tools e.g. HONOS-LD.
- No known tools within UK to look at specific dementia related outcomes for the individual with intellectual disabilities.
How do we know what we are doing is delivering Quality Outcomes across services and for individuals?
What is an outcome?

What are we talking about?

- Outcomes for a whole area?
- Outcomes for a service?
- Outcomes for an individual with intellectual disabilities and dementia?

Definition:

‘a measure of the quality of care, the standard against which the end result of the intervention is assessed.’
Dementia and People with Learning Disabilities

Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia

CR155

September 2009
Self Assessment Toolkit for Area

- Similar approach to ‘Green Light toolkit’ and ‘Challenging Behaviour: a unified approach’.

- Reflects the content of the Report.

- Translates the Guidelines into “Standards you should see if the recommendations are being met”.

- Written as outcomes, not inputs.

- Rate how well your service is meeting each standard **Green** - **Amber** – **Red**.

- Can be used to develop a local Strategy and action plan.
Standards

1. Legal framework & guidance
2. Population
3. Multi-agency dementia strategy
4. Care Pathway
5. Multidisciplinary approach to assessment, diagnosis and support
6. Assessment & diagnosis
7. Person Centred Dementia Care
8. Care management & review
9. Interventions
10. Dementia friendly environments
11. ‘Dying in Place’
12. Choices and rights of people with learning disabilities and dementia
13. Support to family carers
14. Capable workforce
15. End of Life Care
How to use the self assessment checklist

- Identify appropriate stakeholder group.
- Decide which standards the team will look at.
- Review meeting:
  - What are we doing well that meets the standard?
  - What are we *not* doing that we should?
  - Overall rating *Green* – *Amber* – *Red*.
  - Actions we need to take to improve.
How are they being used?

Measuring the practice of specific teams on selected standards:

- Residential and nursing homes.
- Clinical teams that provide assessment & treatment.

City / County-wide strategy (e.g. Sheffield, Surrey)

- Stocktake of current services across the city.
- Identify our strengths and gaps.
- Develop strategic plan.
Quality outcomes in dementia care review
Janicki (2011)

Reviewed recommendations of international dementia organisations and proposed a framework for dementia care quality measurement.

Agencies should promote dementia-capable practices that include:

• Early and periodic assessments.

• Physical modifications in living settings.

• Specialised staff education for stage-adapted care.

• Flexible long term services that recognise and plan for progression of decline and changes in functioning.
Quality Outcome Measure for Individuals with dementia (QOMID)

We wanted to develop a quality of life measure that:

- Could be used with anyone with dementia.
- Was stage specific.
- Reflected the guidance in the BPS/RCPsych document.
- Was fairly quick to administer.
- Could be used in any setting.
- Could be used to help both evaluate quality of life and plan to improve it.

QOMID meets the recommendations for the outcomes framework reviewed by Janicki (2011).
Describing the QOMID

QOMID is Quality Outcome Measure for Individuals with Dementia.

- consists of 17 domains which explore the key areas that ensure that the person with dementia is experiencing a good quality outcomes.

- staged for the three main stages of dementia – suspected/ early; mid and late stage.

- although the domains are the same for each stage, the description of quality outcome may change across the stages to reflect the different requirements as dementia progresses.

The professional completing the QOMID needs to use a combination of results from formal assessments together with their professional judgement to decide which stage of dementia the person is currently experiencing.

We have given brief descriptions of each of the stages and also linked into the care clusters being used in Payment by Results.
<table>
<thead>
<tr>
<th>Domains</th>
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<tbody>
<tr>
<td>1. Person Centred Approaches to Support</td>
<td>9. Carrying out preferred activities</td>
</tr>
<tr>
<td>2. Positive Risk taking</td>
<td>10. Flexibility of support</td>
</tr>
<tr>
<td>5. Interaction with others</td>
<td>13. Health</td>
</tr>
<tr>
<td>6. Emotional reassurance to cope with changes</td>
<td>14. Support from well co-ordinated agencies</td>
</tr>
<tr>
<td>7. Orientation</td>
<td>15. Nutrition</td>
</tr>
<tr>
<td></td>
<td>17. Continence</td>
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</table>
Who should complete the QOMID?

- The QOMID should be completed by the professional in discussion with the relevant people for each stage of dementia.

- Wherever possible, and depending on ability, the person with dementia should be asked how they would rate their experience in each domain.

- Additional information for the professional to make an inclusive judgement may come from family, support staff, advocates, care managers or anyone else involved with the person and their support.

- The person completing the QOMID should record the evidence for their decision for each domain.
### Example of a domain

<table>
<thead>
<tr>
<th>AREA</th>
<th>SUSPECTED / EARLY STAGE DEMENTIA</th>
<th>MID STAGE DEMENTIA</th>
<th>LATE STAGE DEMENTIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. DAILY LIVING</td>
<td>The person is able to complete personal care and daily living activities as much as they are able, but without pressure. The person’s abilities and additional assistance required to help maintain independence are recognised, and the person is supported appropriately e.g. having increased prompting.</td>
<td>The person is able to complete parts of personal care and daily living tasks that they can do and are assisted as necessary so they do not fail. Their support plan details the additional assistance required to help maintain as much independence as possible in a failure free manner.</td>
<td>The person experiences care that is dignified and respectful of them as a person for all their personal care and daily living activities.</td>
</tr>
<tr>
<td>Evidence for rating?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What needs to happen to improve the person’s quality of life in this area?</td>
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<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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</tbody>
</table>

For a | This is rarely achieved for this person | This is sometimes achieved for this person | This is mostly achieved for this person | This is completely and consistently achieved for this person |
Scoring

 Decide which stage of dementia the person currently falls into, based on current assessment and professional opinion.

 Use the column for that stage of dementia and rate each domain using the following rating scale:

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<th>3</th>
<th>4</th>
</tr>
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<td>This is rarely achieved for this person</td>
<td>This is sometimes achieved for this person</td>
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<td>This is completely and consistently achieved for this person</td>
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 For each domain, circle the rating at this current time. All domains should be completed. Record the evidence you have used to make the rating.

 If the domain is rated less than 4, specify what needs to happen to improve the person’s quality outcome in that area of their life.

For a better life
Expected scoring

The aim, in supporting the person with dementia, is for them to have a high quality experience throughout the progression of their dementia.

As dementia is a progressive condition, it is vital to ensure that the person’s changing needs are recognised and met.

This means that as the person moves into each stage of dementia, the quality outcome score for each domain may start at 2 or 3, but as people work together to improve the person’s quality outcome, the scores should reach the maximum of 4 in each domain.

This may mean that scores may fluctuate during the course of the dementia as support ‘catches up’ with the person’s changing needs.

For a better life
What does the overall score mean?

- A score of 60 – 68 indicates that the person has an excellent quality outcome.
- A score of 51 – 59 indicates that the person has a good quality outcome.
- A score of 43 – 50 indicates that the person has an adequate quality outcome.
- A score of 34 – 42 indicates that the person has a poor quality outcome.
- A score of 33 or less indicates that the person has an unacceptable quality outcome.
Forward planning

- The QOMID is designed to help the support team and the professionals to work with the person to both prevent deterioration in quality and to forward plan effective care.

- For each domain that is scored at less than 4, the support team is asked to specify what needs to be put in place to improve the person’s quality outcome for that domain.

- These actions can then be included in the person’s support plan.

- In addition, by looking at the descriptions for the next stage of dementia, the professional can begin to help the person and their supporters to think about what needs to be put in place to maintain their quality outcome.
Validation of QOMID

- Statistical analysis of the data from 73 people show that it is a reliable test and that all domains contribute towards the overall measure of Quality Outcome (Cronbach’s alpha is 0.848).

- 92.5% of participants found it easy or fairly easy to use, and 95.5% said instructions were easy or fairly easy to understand.

- Both majority of participants in OPMH and ID found it easy of fairly easy to assign the dementia status.

- No significant difference in ID v OPMH in easy of use, or understanding the instructions.

- Mean time to administer was 31 – 45 minutes.
Roll out of QOMID

- Writing up results of development and validity work for publication in a journal article.
- Presenting at various forums, conferences etc.
- Want people to use it and submit anonymised data via a survey monkey link so can do further analysis on it.
George

- 51 years old.
- Used to live in a long stay hospital but moved to community in February 1997.
- Lives in a residential home with 3 other men.
- Used to go to a day centre.
- Frequent contact with mother and sister.
- Described as a ‘very friendly man’ and ‘flirty with the ladies’ – especially blondes.
Person centred approaches

- Has a **comprehensive person centred plan** that is updated regularly.
- Always smartly dressed in black shirt and colourful tie, shaved and with after shave.
- Used to like hoovering.
- Often had a comb in one hand and dalek in the other, now a soft toy.
- Loves Dr Who and Elvis.
- Likes his red wine and Guinness, and now has a preference for sweet foods.
- Likes shopping, discos and parties.
- Has regular aromatherapy.
- Recently rediscovered an interest in Chelsea Football club.
Health issues

- Has a Health Action Plan and Hospital Passport that is updated regularly.
- Underactive thyroid.
- Diagnosed with dementia in February 2009.
- Epilepsy started in March 2010.
- Recurrent chest infections and Urinary tract infections.
- Impetigo wrongly diagnosed – actually eczema.
- Now non mobile.
- Has developed dysphagia and has regular input to keep him safe including following dysphagia and choking guidelines, whilst ensuring Happy Eating and good nutrition.
Staff training for whole team in 2009.
Moved bedroom downstairs in autumn 2009.
Home got money for ensuite bathroom to be built in early 2011.
Started attending our specialist ID & dementia day service for 2 days per week in late 2009 on a flexible arrangement.
Life Story book – complex because of Mum’s health issues.
End of Life care planning.
Social life

In a typical month – health permitting now:

» Local shops
» Birthday parties
» Theatre
» Kites club
» Disco
» Pub
» Hydrotherapy
» Curry
» Visits to Mum and sister
» Special outings
Quality of Life

- Dr Who exhibition at Olympia

- Dressage at Paralympics

- Chelsea v Sparta Prague

For a better life
Any Questions?
Contact details

Dr. Karen Dodd
Surrey & Borders Partnership NHS Foundation Trust,
Ramsay House,
West Park,
Epsom,
Surrey KT19 8PB

✉️ DrKaren.dodd@sabp.nhs.uk
📞 01372 205767