

Supporting people with learning disabilities who develop dementia

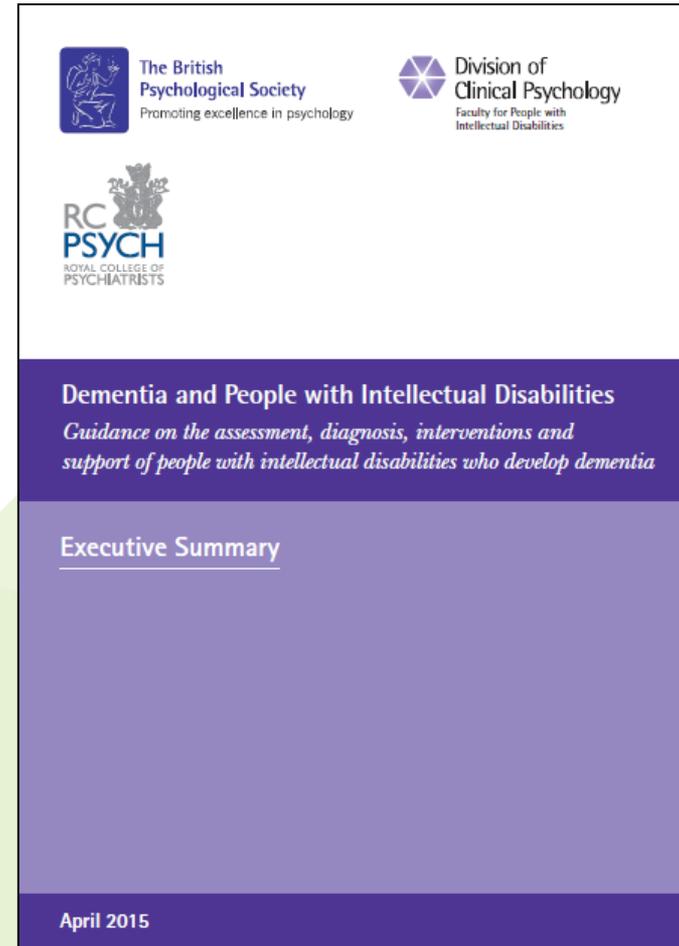
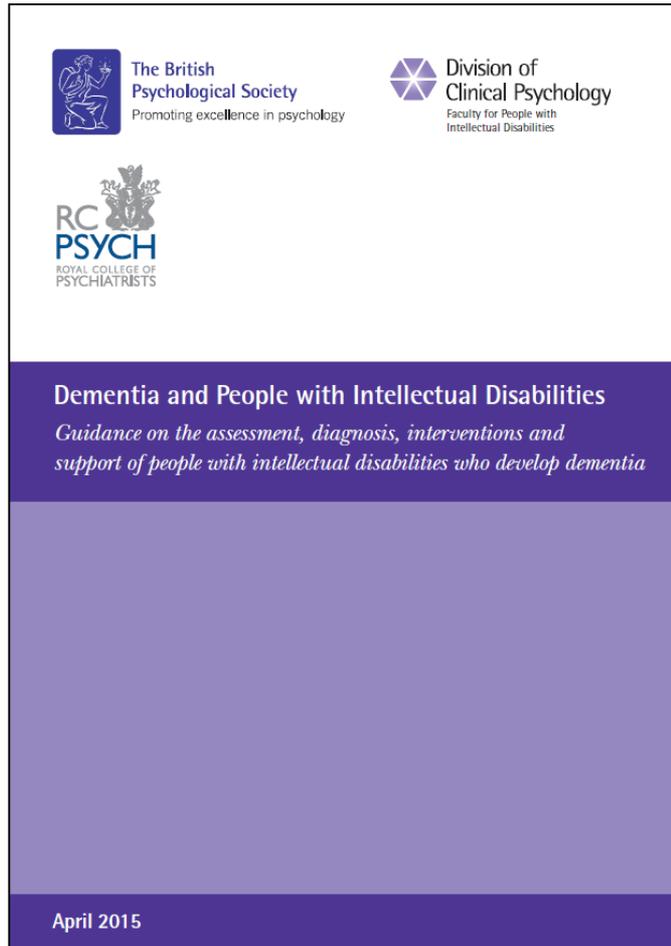
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Learning Disabilities
Services

Updated guidance



Presentation in people with LD

- There is more likely to be a range of pathologies resulting in dementia, as is the case in the general population, and for the same reason differences in presentation and the course of dementia.
- The presentation and course of dementia among people with mild learning disabilities is likely to be similar to that which is observed in the general population.
- The presentation and course of dementia in people with more severe learning disabilities may initially be atypical and present with changes in behaviour and for this reason dementia may not be suspected. As the illness progresses careful questioning of staff and carers may identify evidence of developing memory and functional impairments.

The link with Down's syndrome?

- Down's Syndrome is a genetic disorder caused in 96% of cases by a extra copy of chromosome 21
- Evidence of triad on post mortem over the age of 30 years
- Chromosome 21 has the Amyloid Precursor Protein (APP) gene
- Gene for Family history of Alzheimer's is also on Chromosome 21 (and 1 and 14)
- ApoE status may be relevant

Presentation in People with Down's syndrome

- Most common form of dementia in people with DS is Alzheimer's disease. It is known that the brain pathology of Alzheimer's disease is almost universally found in later life in people with Down's syndrome.
- Vascular disease, and the risk of vascular dementia is rare.
- Dementia in people with DS may present atypically with changes in behaviour and/or personality that can precede the full clinical picture of dementia by some years.
- Dementia in people with Down's syndrome may be associated with the onset of seizures for the first time in that person's life (78 – 98%).

Atypical presentations in people with DS

- Anecdotal reports of people with DS in teens or early adult who deteriorate, often after a life event, and never recover, but plateau.
- Superficially resembles dementia or depressive illness but it neither seems to progress (as would be expected with dementia) or resolve (as would be expected with depressive illness with appropriate treatment).
- The clinical picture is of the development of a general slowness in mental and/or physical activity, apparent loss of interest in previous activities, and a lowered level of functioning.
- Unclear how such problems should be best conceptualised.

Current Prevalence and Survival

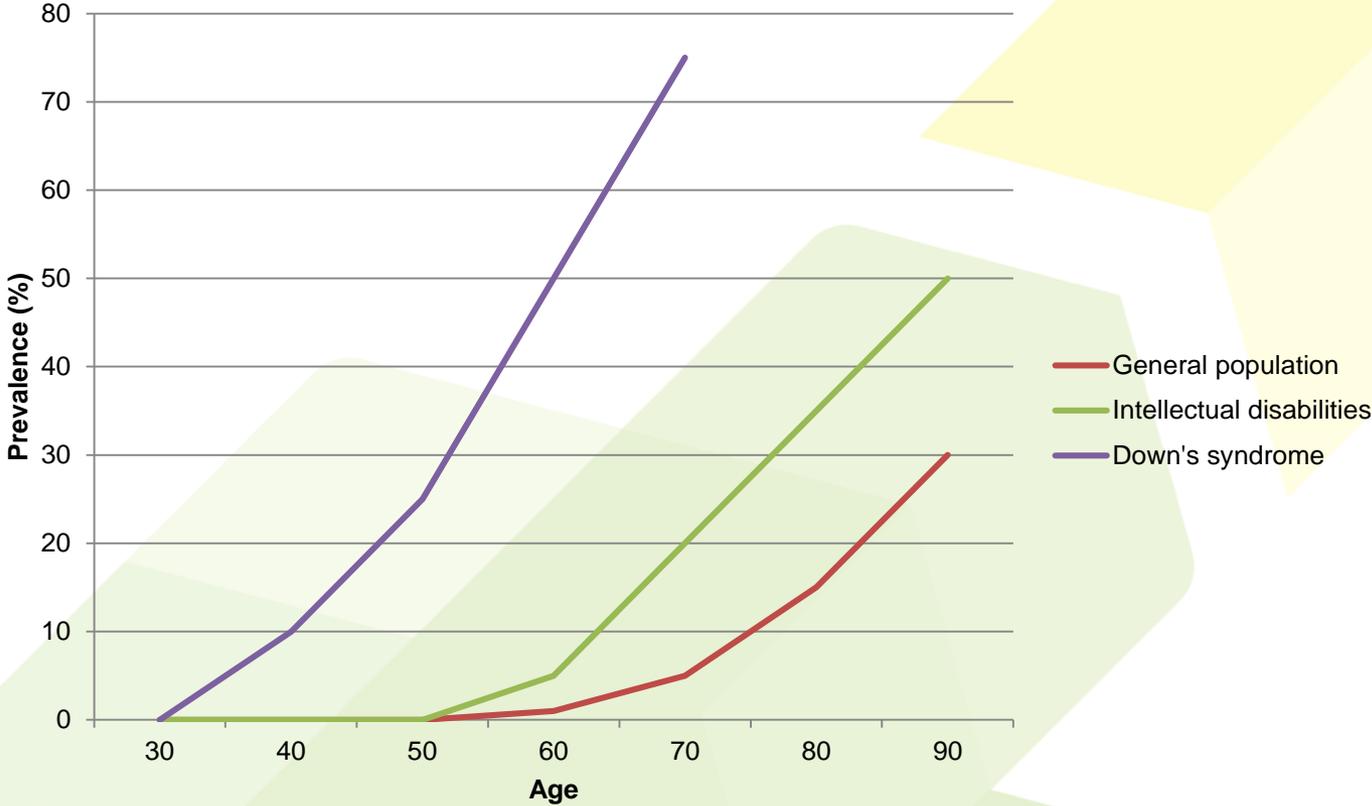
London Consortium study

- Median age of onset = 55.4 years
- 50% of those who develop dementia are diagnosed in their 50's
- Median survival time= 4.1 years (95% CI: 3.6, 4.6)
- Age at diagnosis highly predictive of survival time
- Gender is not predictive

Age of diagnosis	Median (95% CI)
Under 50	5.6 (2.7, 8.4)
50-59	4.4 (3.8, 5.0)
60+	2.6 (1.5, 3.7)
All	4.1 (3.6, 4.6)

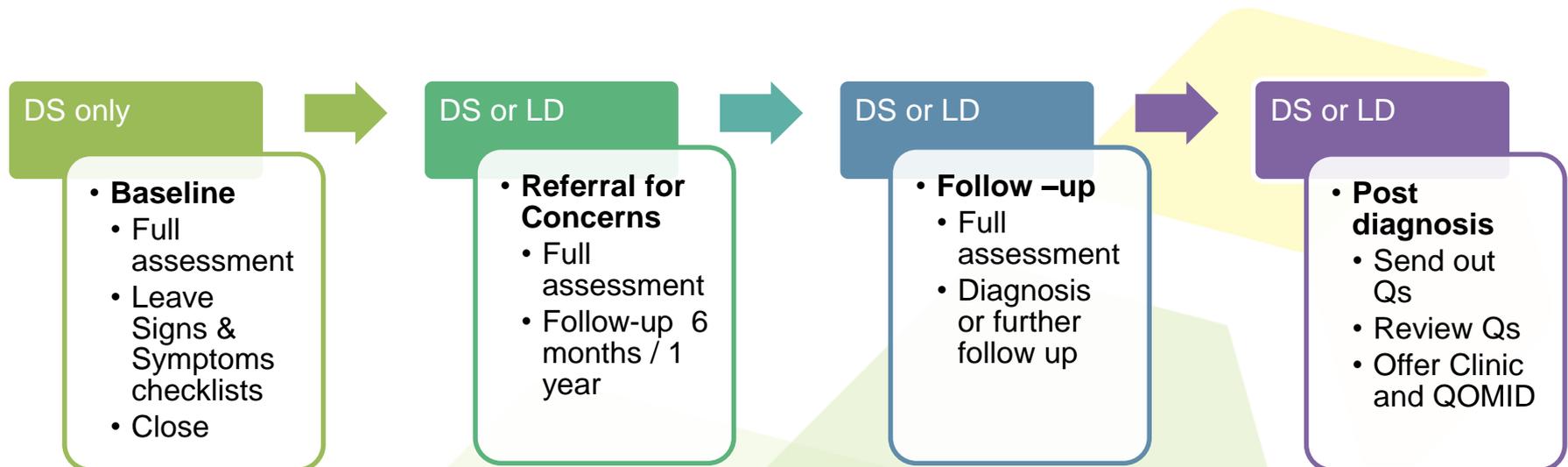
Dementia Prevalence Rates

Comparison of dementia prevalence rates by age



Referral pathways

Where in the pathway is the person?



Baseline assessment?

- Record of people's skills and abilities at peak of their functioning
- History to date
- Is the person stable – or is there already issues to be considered
- Highlight signs and symptoms that may indicate dementia in the future
- Identify any other health / social care issues
- Establishing pre-morbid skills, abilities and personality can be challenging in the learning disabilities population due to:
 - variance in cognitive functioning and abilities,
 - frequent poor record keeping from childhood
 - the possible lack of consistent involvement of family or staff throughout the person's lifespan.
- Current recommendation is baseline assessment at 30 for people with Down's syndrome, but not to do baselines for other people with LD.

Recognising early signs

- Signs of early dementia can be subtle and require careful observation to identify concerns in a timely way.
- Families and staff carers can often be so close to the person that they become less able to recognise minor changes in functioning through adapting to the person's needs.
- Looking for change from pre-existing abilities
- For people with more severe and profound LD – may be looking for specific changes e.g. development of epilepsy, change in day/night routine



Early Signs of Dementia in People with Down's Syndrome Checklist

People with Down's Syndrome are more likely to develop a 'frontal like' dementia prior to developing Alzheimer's disease.

The most common early signs to look out for are changes in:

- Mood
- Behaviour
- Executive function e.g. planning, initiative, problem solving, reasoning
- Personality
- Social skills

Signs of Alzheimer's disease are when the person shows the following changes that are different from how they normally are:

- Anxiety in unfamiliar places
- Loss of daily living skills
- Deterioration in short term memory e.g. forgetting what they have said, losing their belongings, asking the same question repeatedly
- Loss of interest in previously enjoyed activities
- Reduced communication
- Difficulty in finding the correct word
- New or increased confusion and/or disorientation
- Changes in sleep pattern
- Difficulties with steps, stairs and kerbs, changes in colour of flooring due to depth perception problems
- Increased walking about without a clear reason

Misdiagnosis of dementia can occur because the signs are the same as those for a number of treatable conditions e.g.

- Depression
- Lack of sleep
- Urinary Tract Infection
- Effects of medication
- Thyroid problems
- Untreated pain
- Dehydration
- Constipation
- Hearing/Visual impairment

Please see the table attached to help think about possible causes and actions to take.

It is recommended that you visit the GP to express concerns in the first instance to rule out any of the above, prior to contacting us for an assessment.

For a better life



What might the following early signs indicate?

Obtaining a correct diagnosis is extremely important in terms of ensuring the person receives the correct treatment or intervention. Many early signs of dementia can also be the result of other factors. Below is a list of other conditions that may mimic early signs of dementia. Familiarise yourself with these and consider if any of them could be a factor in changing the person's behaviour.

Stress	Thyroid	Depression	Sensory Impairments	Physical Changes	Dementia
Concentration problems	Lethargy	Disturbed sleep	Ignores instructions	Withdrawal	Loss of recent memory
Irritability	Weight gain	Loss of appetite	Mobility problems	Aggression	Loss of skills
Decline in abilities	Cold intolerance	Low mood	Loss of confidence	Mobility problems	Changes in mood
	Changes in skin and hair	Withdrawal from usual activities	Shouting or raised voice	Self-injury	Orientation difficulties
		Tearful		Pacing	Sleep disturbances
				Crying	Language difficulties
				Screaming	Depth perception problems
If you notice any of these changes, you should carry out the following actions...					
Identity cause of stress, such as life event - e.g. family death, illness	See GP	See GP	Complete full health assessment	See GP; medical history and physical investigations	See GP; medical history and physical investigations
Offer support and reassurance	Annual blood tests	Medication and/or counselling	Check eyes, ears and feet	Medication changes	Referral to Community Team for People with a Learning Disability
	Is it an under or overactive thyroid?		Access appropriate services	Check for diabetes	
	Medication			Check for pain	
				Check for urinary tract infections	
				Check for nutritional deficiencies/dehydration	

Concerns

- Is the person the same as they were previously? Identify the changes against known pre morbid functioning e.g. baseline if DS, or other previous assessments.
- If there are changes – what has caused the change?

Remember dementia is always a diagnosis of exclusion

May be able to diagnose at this stage – but more likely there will be actions and need to follow-up again

Conditions that Mimic Dementia

➤ Physical Health issues

- Uncontrolled Epilepsy
- Nutrition – vitamin B12 & Folate
- Electrolyte abnormalities
- Hypothyroidism

➤ Sensory Impairments

- Visual Impairments (recognition, lost skills)
- Hearing Impairments (misunderstanding)

➤ Mental Health Problems

- Depressive illness (pseudo-dementia)
- Psychotic disorder (decline in function)
- Chronic Anxiety (catatonia)

➤ Medication

- Anticholinergics, psychotropics, Anti-epileptics's, Pain meds, antihistamines and benzodiazepines

Conditions that Mimic Dementia II

➤ Sleep Disturbance

Sleep Apnoea or other sleep disturbances

➤ Life Events

Loss of parents, moves, day-care changes etc

➤ Impact of poor social / physical environment

Loss of skills and regression

➤ Abuse

Loss of skills and regression

➤ Acute Organic Brain Syndrome

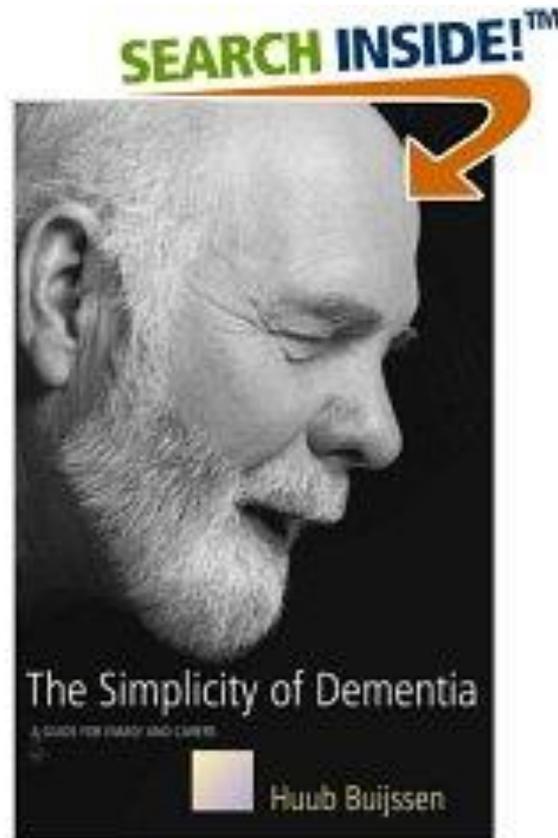
Confusional state secondary to pain, chronic infection or head injury

Assessment with concerns

- Nature of the presenting problem(s), origin, rate/pattern of progress (sudden or gradual), presence of seizures and other associated conditions, impact on the person's overall functioning and personality.
- History of significant physical and medical history including past and present medical conditions, e.g. diabetes, hypertension, thyroid or cerebrovascular disease, B12 deficiency. Family history: dementia or other mental health and medical conditions (particularly in first-degree relatives).
- History of or current presence of psychiatric symptoms such as depression, anxiety or other mental health problems.
- Direct cognitive assessment, and physical health checks – caution re neuroimaging.
- Information gathering should be undertaken through a combination of informant interview (preferably with a family member, when relevant and appropriate) or an informant who has known the person well for a period of six months at least) and directly from the person where possible.

Social / Environmental assessment

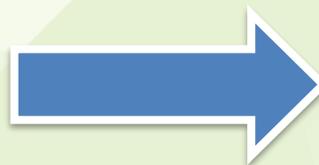
- Quality of the person's physical environment.
- Staffing levels (day and night).
- The mix of people with intellectual disabilities in the residential and day care settings.
- Moves and changes to residential / day / leisure
- Quality and quantity of day activities.
- Staff characteristics: attitudes and competence, including consistency of approach.
- Scrutiny/review of historic/current support package.



The 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.
- The main consequence of disturbed encoding is that the person is unable to form any new memories for the things they experience or for things they are told.

Short term memory
30 seconds



Long term memories
Life long memories

Consequences of disturbed encoding

- Disorientation in an unfamiliar environment
- Disorientation in time
- The same questions are asked repeatedly
- The person quickly loses track of conversation
- The person is less able to learn anything new
- The person easily loses things
- The person is unable to recall people they recently met
- Appointments are quickly forgotten
- People experience anxiety and stress

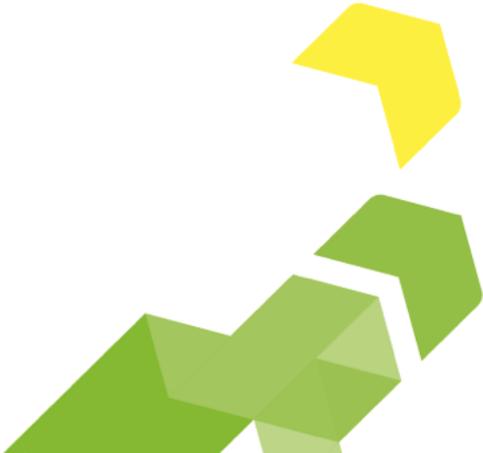
The law of roll-back memory

- Long-term memory contains all the memories that have been acquired from most recent memories working back toward childhood memories.
- When you develop dementia you will be unable to form any new memories after this time.
- 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'.



Consequences of roll-back memory

- Loss of daily skills such as using kitchen appliances
- Memory loss for events beginning with the most recent
- Decreased social skills and inappropriate behavior
- Decreased vocabulary and inability to find words.
- Disorientation towards people: inability to recognise family and relatives
- The person may begin to have 'flashbacks' and see people from their past
- Self care skills will begin to deteriorate
- Changes in personality
- Person believes that they are younger and that time has actually 'rolled back'



Social model of dementia

- Proposes that people have an impairment, but are disabled by the way they are treated by or excluded from society.

Advantages of this framework are that carers and staff will understand that dementia is:

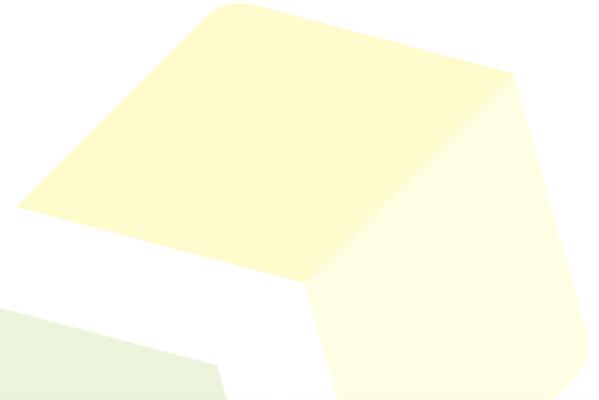
- not the fault of the individual
- the focus is on the remaining skills rather than losses
- the individual can be fully understood (their history, likes / dislikes etc)
- the influence of an enabling or supportive environment
- the key value of appropriate communication
- opportunities for stress-free and failure-free activities

What does this mean in practice?

- This means that the responsibility to continue to reach out to people with dementia lies with people who do not have dementia.
- Carers and staff need to change their approach to 'go with' the person and their continuing changes.

Supporting documents

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



This is me My Care Passport

It should be kept with me and brought with me into any care setting, including hospital.

Click here to add your photo

My name is:

I like to be known as:

Please return my passport to me when I go home.

This is essential reading for all staff working with me. It gives important information about me. This passport should be kept visible and used when you talk to me or think about me.

Things you must know to keep me safe

Things that are important to me

My likes and dislikes

This passport is a pdf file that can be typed into, saved and updated using Adobe Acrobat Reader. Go to www.surreyandborders.nhs.uk to download free of charge. You could also print it off and write on it.

More basic information about me

This passport needs to be updated if my needs change.

Where I currently live:
For example - supported living or my family home.

Hours of support I get each day:

Who to contact for more information about me:
Please say name, role and contact phone number.

Other key professionals involved in my care:
Please say name, role and contact phone number.

Key person / people to liaise with about my admission and discharge:

This passport was filled in by: Date:

Things you must know about me

1. Adverse drug reactions, allergies or intolerances.
Please give details including what my reactions would be.

2. Communication - How well I use and understand speech
Other ways I communicate - signing, pictures or other languages?
How I show how I feel, how I communicate yes and no.

3. Food and drink - Food allergies / intolerances and help choosing
Do I need help filling in menus? How I make food and drink choices.
See also the likes and dislikes section.

Things that are important to me

Important people	Level of support I need when well
Family, friends & staff who support me.	Who needs to stay and how often.
<input style="width: 100%; height: 50px;" type="text"/>	<input style="width: 100%; height: 50px;" type="text"/>

How I use the toilet when I am well - e.g. continence aids and getting to the toilet.

Personal care - support I need with things like dressing, washing and teeth cleaning.

Moving around - for example posture in bed, walking aids and wheelchair.
Do I need help with moving around?

Sleeping - my sleep pattern / routine / time of waking.

My likes and dislikes

Things I like	Things I don't like
Could include: Music, TV, foods, activities and how I relax.	Could include: Things that worry me, foods, activities and ways I don't like being treated.
<input style="width: 100%; height: 100px;" type="text"/>	<input style="width: 100%; height: 100px;" type="text"/>

My history - What is important that you know about my life (past and present)
Please also use the space for any further information.

Based on a previous 'Thought Passport' the version is designed to be used for all people within a variety of care settings. The resources developed together by Surrey and Borders Partnership for mental health Foundation Trust, Alzheimer's Society, The Care and Older Adults Services, Surrey County Council, Hospital and the Surrey Alzheimer's Association. This passport was designed by The Older Communities People Link using our template framework. Email: info@communitiespeople.co.uk for more information.

What is the challenge?

90% of Catastrophic Behaviours in people with Dementia are induced by Carers and the Environment.

Brawley E (1997) Designing for Alzheimer's Disease.
Strategies for creating better care environments.

Establish a 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.
- can only be achieved by having a thorough knowledge and understanding of the person and their history. This can be aided by the ongoing use of Life Story work.
- Need to maintain all the elements of normal daily living to retain skills for as long as possible.

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

Meeting changing needs

- As the dementia progresses, the emphasis of care changes from enabling the person to maintain their skills with support to increasingly taking on tasks for the person with dignity and respect.

At the early stage of dementia, this will involve:

- reminding the person of the day, time, place;
- simplifying routines and reducing choices;
- introducing memory aids such as diaries, timetables and objects of reference;
- simplifying communication,
- using additional cues and prompts.

As the dementia progresses, care changes to:

- trying to preserve abilities for as long as possible using techniques of reminiscence,
- identifying favourite activities and strengths,
- finding failure-free activities.

Health monitoring becomes essential e.g.

- attention to weight,
 - adequate nutrition and hydration,
 - physical health including epilepsy, continence, pain and mobility are all vital.
- It is vital that people are involved in all aspects of normal daily life e.g. cooking, cleaning, laundry etc to maintain skills and keep a normal daily pattern.

- Towards the end of the person's life, swallowing and dysphagia, skin and pressure sore care, moving and handling all become paramount.
- Even at the end stage of dementia it is important that the person has positive interactions throughout their day.
- The tasks of daily living often become the activities of the day, and should be pleasurable and enjoyable for the person. Appropriate touch and verbal interaction are essential.

Possible Interventions

After implementing the philosophy of care, other approaches include:

- Activities and Intervention
- Anxiety and stress reduction
- Life story work
- Reminiscence
- Reality orientation
- Validation
- Understanding behaviours
- Medication

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.

Suggested interventions

Kalsy –Lillico et al., (2012) reproduced in Watchman (2014).

Early Stage	Early–Middle stage
Board games: card games such as snap are good, as are large sized dominoes	Music – play something that resonates, is liked by the person and has a good bass and beat
Ball games: throwing soft balls to each other, standing or sitting	Dance – chair dancing is good, swaying and rocking in time to music
Discussion: about people, places and things	Art and ‘pottery’ – working with dough, clay, plasticine or sand
Relaxation: progressive relaxation, massage or aromatherapy activities	Movement – guided walks, progressive relaxation
Arts and crafts: painting, coloring in, making bean bags, poster	Drama
End-product activities – anything where there is an immediate end results such as flower arranging, drawing, cooking, baking	Reminiscence – using familiar items, mementoes touch, taste, smells, sounds, pictures or photos that reminds people of times gone by
Use visual planners to structure activities/day	Storytelling – talking about old friends, stories about special times, memories or what’s on TV
	Spiritual or religious activity

Middle Stage	End Stage
<p>Movement and exercise – can be done standing or sitting</p>	<p>Smiling and laughing – don't underestimate this as an activity</p>
<p>Multi-sensory environments – use lights, sounds, smells, touch, Snoezlen</p>	<p>Singing – humming along to popular tunes, radio jingles or TV adverts</p>
<p>Massage – hand and feet spa treatments</p>	<p>Stroking – positive touch of people and objects that have different textures</p>
<p>One-step cooking tasks – such as mixing items, peeling food</p>	<p>Gentle rocking – can relax and establish physical contact</p>
<p>One step gardening tasks – such as watering plants, digging pots</p>	<p>Holding – as above</p>
<p>One-step daily living tasks – such as plumping up cushions</p>	<p>Cuddling – as above</p>
<p>Walking – along routes that are circular with focus points</p>	
<p>Stacking and folding – clothes, papers and magazines</p>	
<p>Soft toys – touch can help anxious feelings Baths, bubbles, balloons – remind people of fun</p>	

Anxiety and stress reduction

- As people develop dementia, one of the first symptoms often seen, caused by the effects of disturbed encoding, is anxiety.
- This can manifest itself in many ways e.g. The person may become very anxious about leaving familiar environments. The person may not remember where they are going or why, they may resist putting on their coat, or demand to return to their familiar setting.
- Staff and family carers need to firstly recognise why the person has become stressed and anxious, and look at solutions to help reduce the person's level of anxiety.
- This can be achieved by a variety of techniques including:
 - reassurance and verbal reminders,
 - the use of visual aids to remind the person where they are going,
 - the use of relaxation techniques that are already familiar to the person e.g. aromatherapy (Harrison & Ruddle, 1995), breathing exercises and imagery and visualisation exercises.

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'

- Need a thorough knowledge and understanding of the person and their history. This can be aided by the use of Life Story work (Gibson, 1994).
- Life story work 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 (Kerr, 2007).
- The process of talking to people about their memories, collecting objects and pictures are the important aspects, rather than 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 learning disability, a lifestory book would remind any new carers that behind the debilitating illness is a person who enjoyed certain things in 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 learning disabilities and dementia to find anchors with their past and to help steady and engage the person (Kerr, 2007).
- 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 (Woods *et al*, 2006).
- There is less written about its use with people with learning disabilities (Puyenbroeck & Maes, 2002; Gibson, 2006), but anecdotally has become valuable in its use with people with learning disabilities and dementia.

Reality orientation v validation

- There are conflicting views about the use of reality orientation and validation approaches with people with learning disabilities and dementia.
- Both are requisites of good care.
- 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.
- Reality orientation needs to be used in a humanistic, sensitive and individualised manner. The home must be one in which it is worth being oriented e.g. diary of days events, photograph/ picture on bedroom door, arranging clothes in correct order for dressing.
- Reality orientation should enable people to retain control where possible, to reduce stress and facilitate their hold on reality, if that is in their best interests.

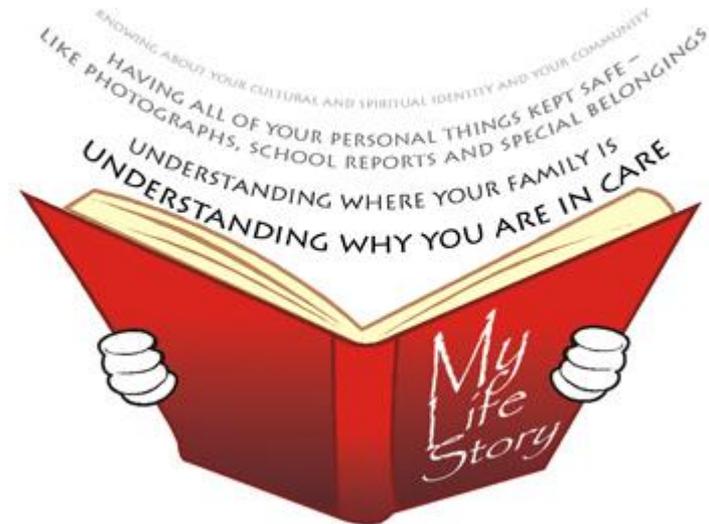
- As the dementia progresses, the person with dementia does not remember events that have happened in the past as their memory 'rolls back' to an earlier time.
- This frequently results in the person asking for people who either are no longer alive, or part of their lives. This is where the controversy exists.
- Some staff and professionals believe that we should not 'collude with false reality' and that we should always tell people the truth, regardless of how painful that is for the person.
- e.g. the person with dementia asks staff repeatedly when their mother is coming, even though in reality she has died.
 - To remind the person of the truth reminds them of their loss.
 - The person will forget what they have been told, and will ask again therefore repeatedly experiencing feelings of loss.
 - Staff need to consider what has been gained for the person by repeatedly reminding them of their loss.
- Kerr (2007) who writes that 'To tell someone with dementia the truth when it is going to cause immense stress and grief is cruel and unacceptable'.
- Barbara Pointon recommends that if the person is unable to enter our world, then we must enter their and affirm it.

Support to family carers

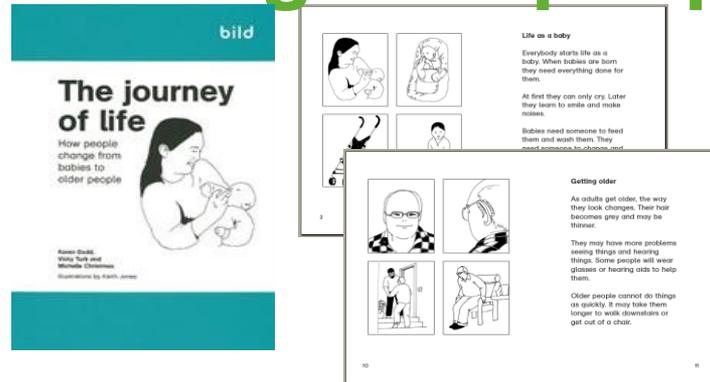
- Family carers are supported to understand and support their relative who has dementia. Their needs as carers are met.

Need to consider:

- Information needs
- Co-dependency
- Engagement issues
- Life story work
- Short breaks
- Knowing when to ask for help

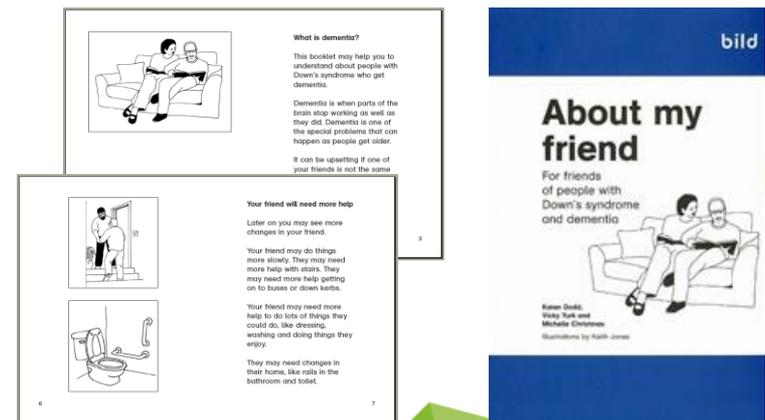
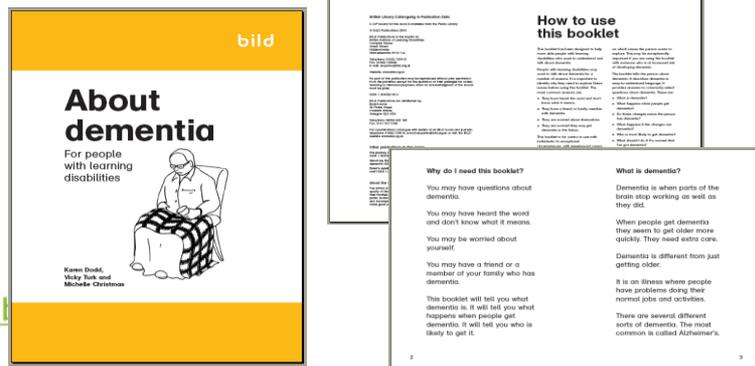


Working with people with DS



- ❖ These booklets can be used with individuals or in small groups.
- ❖ It is recommended that people are taken carefully through the booklets before being given to them, as talking about these sensitive issues can be very emotional for people.

- ❖ Three booklets have just been published by British Institute of Learning Disabilities.
- ❖ Reading the booklets and discussing their contents with carers should help people come to terms with changes they may be experiencing, and other age related issues.



Dementia friendly environments

- Most environments where people with learning disabilities 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:

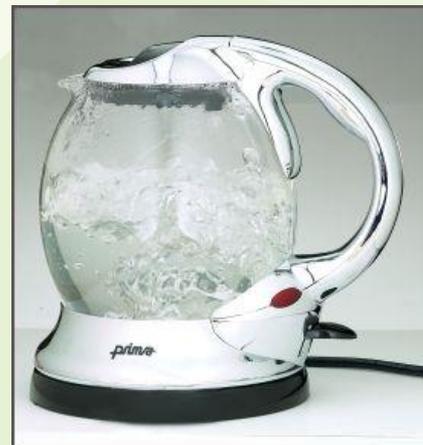
- **Calm** – noise (internal and external), pace, colour
- **Predictable and making sense** – cues, signposting, no surprises
- **Familiar** – homely, long term memory
- **Suitably stimulating** – noise, views
- **Safe and risk assessed** – access, stairs, hazards

Colour

- Need good contrasts
- Light reflecting colours
- Use colour to define spaces



What not to do!



For a

Bedrooms

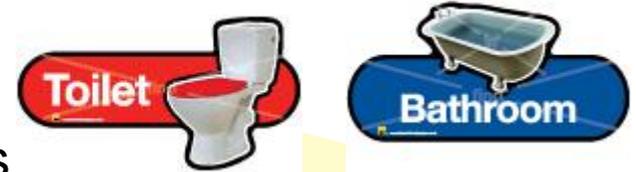
- Finding it!
- Good night sleep
- Colour contrasts – bedcovers, furniture, carpet
- Blackout curtains
- Reduce patterns
- Traditional lights
- Coverable mirrors
- Dementia friendly wardrobes
- Personal items



Night time care

- Night lights or lamps activated by movement sensor
- Commodes may be useful if a person cannot reach the bathroom, but they may forget what it is for or not recognise it.
- Avoid waking the person up during the night to see if they have been incontinent of urine.
- A sensor mat in the bed can help
- Modern body-worn continence products will contain urine and protect the skin for the night.
- Waking night staff should feel free to wear a dressing gown.

Bathrooms and toilets



- Finding them from seating areas / bedrooms
- Contrasting colours will assist a person with dementia to use bathroom facilities.
- Toilet seats, handrails and towels should all be easy to identify.
- A bar of soap (which should be a different colour from the sink it sits on) can prompt a person to wash their hands when they might forget otherwise.
- Bathrooms should be furnished and decorated to promote a pleasant experience. Avoid a sterile hospital-like appearance that is pale and where it is hard to see things.



Planning for the future

Preferred option:

- **‘Dying in place’** where the person can stay where they are currently living with appropriate supports adapted and provided. This means that the person stays with what is familiar in their long-term memory.

Compromise option:

- **‘Moving to more specialist learning disability provision’** where the person has had to move from their current home, but moves into provision supported by learning disabilities services.

Least preferred option:

- **‘Referral out of learning disability services’** where the person will be moved to services for older people, either residential or nursing.

In some instances it is not possible to maintain the person in their existing home:

- It may be that the design of the building is inappropriate and cannot be changed.
- The person may be being cared for by older family carers who may not be able to continue caring as the needs of the person increase, or their own health changes.
- Risk assessments should be completed regularly to ensure that the environment remains safe for both the person and their carers.
- Staff may reach a 'tipping point', where there are insurmountable problems with the placement (often the quality of life for the other residents or staff issues).
- Funding may be an issue.

Deciding when to move

- Deciding when to move someone is always a very difficult decision.
- Clearly the environment is less important if the person can move with all their existing carers who can ensure an ongoing consistency of approach. However this is rarely achievable.
- Once a move is inevitable, debates arise about the timing and the best environment to move to.
- Moving people in the early or middle stage of dementia may increase the rate of deterioration
- Late moves can lead to a significant increase in the risk of early death
- Multiple moves should always be avoided.

Introducing the QOMID

Quality Outcome Measure for Individuals with Dementia

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

Example of a domain

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA	
8. DAILY LIVING	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.	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.	The person experiences care that is dignified and respectful of them as a person for all their personal care and daily living activities.	
	1 2 3 4	1 2 3 4	1 2 3 4	
Evidence for rating?				
What needs to happen to improve the person's quality of life in this area?				
	1	2	3	4
	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

For a

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.
- Available at

http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm

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:

1	2	3	4
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

- 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.



Real life example

- James is a 58 year old man with Down's syndrome and in mid stage dementia. He lives in a 6 bedded LD residential home in a complex of 4 homes, which have been through difficult times. It is now more stable and the manager of the complex has now decided that this home will become a specialist LD & dementia home.
- Undertook the QOMID with staff, family and James
- Overall score was 57 – good quality outcome

Identified areas of need

	Domain	Score	Actions required
1.	Person Centred Approaches to Support	3	Life Story Book needs to be done – assistant psychologist, family and staff
4.	Consistency of approach	3	Guidelines for morning and evening routine need to be put on the inside of James' wardrobe door, and all staff informed.
7.	Orientation	2	More picture cues are needed. Larger staff picture board, daily timetable, picture menu, pictures for events /shopping
9.	Carrying out preferred activities	3	Further favourite activities have been identified from James' earlier years with family. Brother to make James a Shovehappy board. Outings to Bognor / Wittering. Putting green – Littlehampton. Putting set for garden

	Domain	Score	Actions needed
11.	Environment	2	Some work has started but a fuller programme of environmental modifications is needed e.g. red toilet seats, more signage etc
13.	Health	3	DisDAT to be completed re non verbal ways of assessing distress for James. More attention to be paid to need for Vitamin D and DH guidance
16.	Mobility	3	Shoes need to be checked regularly for fit, and staff to check walking regularly
17.	Continence	2	Mattress on bed needs to be sorted Pads need to be sorted – pull ups during the day and flexitab at night Staff to ensure bedtime routine is followed. Toileting programme and monitoring chart to be started asap Community Nurse to follow-up re continence products and funding

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