

The dementia journey for people with learning disabilities: from early signs to supporting people well.

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Learning Disabilities
Services

What this webinar will cover

This webinar will explore the journey for a person with learning disabilities who develops dementia.

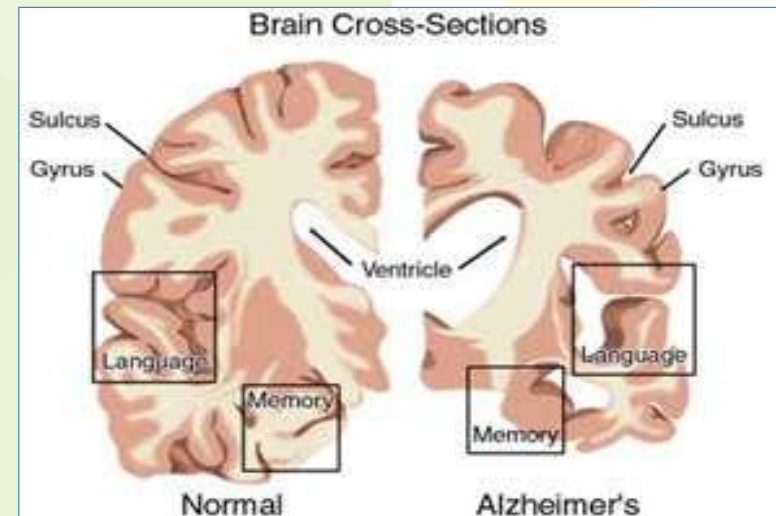
By the end of the webinar, participants will be able to:

- identify the early signs of dementia,
- how to understand dementia in people with learning disabilities;
- what needs to be in place to support people through the course of their dementia;
- the importance of adapting the support;
- how to understand and minimise the impact of behaviours that are viewed as difficult.

Identifying the early signs of dementia

What do we mean by dementia?

- Dementia is an umbrella term used to describe a collection of illnesses with a similar pattern of symptoms.
- There is not a single illness called dementia. It is thought that there are over 100 types of dementia.
- Dementia is the *progressive* decline in four main thinking abilities: memory, language, perception/attention, ability to plan and organise - executive functions. This means that the symptoms will get worse over time



Presentation in people with LD

- Can develop any type of dementia.
- For people with mild learning disabilities, the dementia signs and symptoms and progression is likely to be similar to that which is observed in the general population.
- People with more severe learning disabilities may present differently when they develop dementia e.g. with changes in behaviour. Dementia may not be suspected, and staff / families should look for small signs of change in memory or changes in function.

Presentation in People with Down's Syndrome

- Most people with Down's syndrome who develop dementia have Alzheimer's disease.
- 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%).
- Changes in executive function seen first e.g. initiation, planning. The person may still be able to do tasks but need more prompting, different pace

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...					
Identify 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	

What should you do if you are concerned that the person is developing dementia?

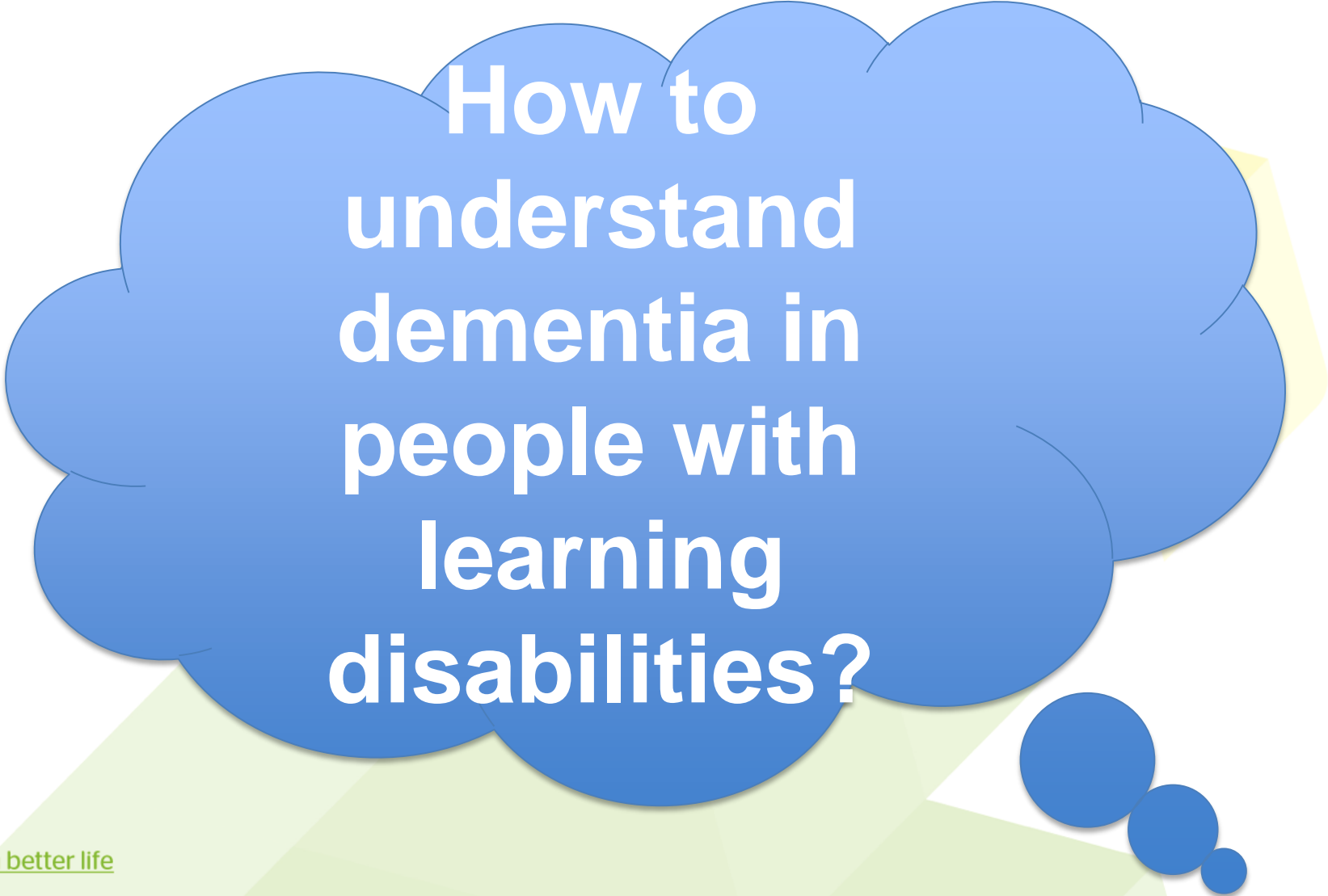
- Take the person to their GP
- GP should check physical health issues and undertake necessary health checks including, where possible, relevant blood tests
- GP sends results of physical health checks and referral to the CTPLD
- CTPLD will invite the person to attend a screening assessment
- Further assessment will be carried out as required
- Report sent to person, carers/ staff and GP

Lots of conditions can mimic Dementia

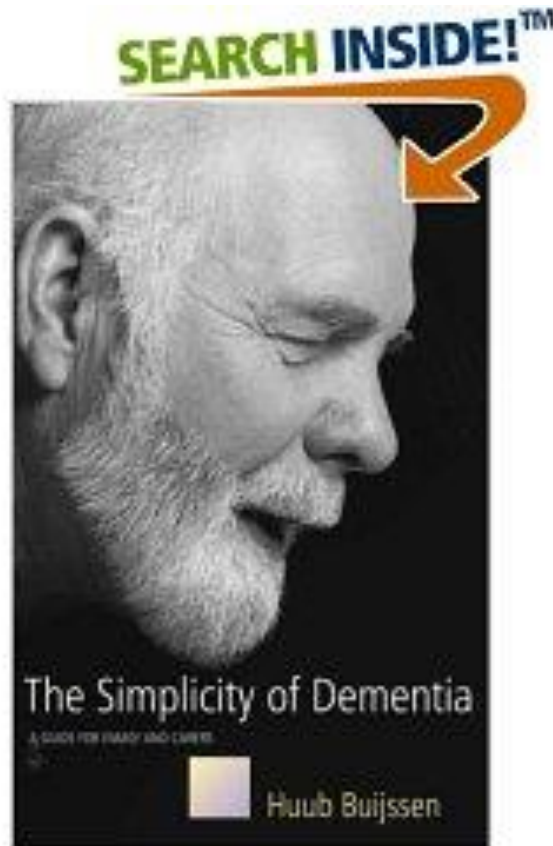
Need to check and treat:

- thyroid problems - thyroid should be tested annually
- depression and other mental health problems e.g. chronic anxiety, psychosis
- sensory difficulties – both vision and hearing which should be checked at least every 2 years
- physical problems e.g. cancer, infections
- sleep problems e.g. sleep apnoea or other sleep disturbances
- environmental changes
- neurological conditions e.g. uncontrolled epilepsy, head injury
- psychological problems e.g. abuse
- polypharmacy – people taking many medications can show side effects that mimic the early signs of dementia

For a better life Only if all these have been checked, and symptoms persist should you begin to think dementia.



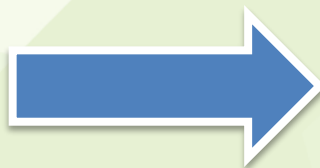
How to understand dementia in people with learning disabilities?



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'



**What needs to be
in place to
support people
through the
course of the
dementia**

What happens over time with dementia

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

If it is dementia?

- Dementia is a **progressive** disease
- Wherever possible people with LD and Dementia should **remain in familiar in environments**
- Every effort should be made to **maintain home life** as dementia progresses
- May necessitate **environmental changes** and **adaptations** to support the person
e.g. an increase in staffing levels
- Careful **planning** about the appropriate level of support is required
- Further **whole team training** for staff/ carers on meeting people's changing needs

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.

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'.

The importance of adapting the support

- Staff/ Carers 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.
- Need to adapt support as the dementia progresses

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

How can we support people?

After implementing the philosophy of care, other approaches include:

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

Importance of environments

- Environments play a huge role in the wellbeing of people with dementia
- Dementia enabled environments can prevent and reduce behaviour
- Changes needn't cost a lot but make a huge difference

Environments may need to be altered to be:

- **Calm**
- **Predictable and making sense**
- **Familiar**
- **Suitably stimulating**
- **Safe and risk assessed**

Door & Drawer Sticker Pack



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.

Anxiety and stress reduction

- One of the first symptoms often seen, caused by the effects of disturbed encoding, is anxiety.
- Recognise anxiety and look for solutions
- Use a variety of techniques:
 - reassurance and verbal reminders,
 - visual aids to remind the person where they are going,
 - relaxation techniques that are already familiar to the person
 - aromatherapy
 - breathing exercises
 - imagery
 - 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.
- The process of talking to people about their memories, collecting objects and pictures are the important aspects, rather than the final end product. Helps with engagement of family members and friends
- 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 will 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
- Use music, objects, activities as a way of engaging people.

Reality orientation v validation

- 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'.
- Use cues, gentle reminders, photos and pictures to help the person to engage with the world around them 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 or about places that are no longer alive, or part of their lives.
- It is now accepted that 'telling the truth' is not the best approach.
- We need to validate the person's feelings without making them more stressed
- Barbara Pointon recommends that if the person is unable to enter our world, then we must enter their world and affirm it.

how to understand
and minimise the
impact of
behaviours that
are viewed as
difficult.

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.

Behaviour that challenges



Understanding behaviours

- The problem behaviour may be transitory to the current stage of the person's dementia and not need an intervention.
- The situation should be viewed through the eyes of the person with dementia, i.e. their current reality.
- Continual correction by staff/carers of a false reality (e.g. person with dementia asking when a dead parent will visit) will not reduce their immediate confusion and distress.
- Behaviours may be due to:
 - person to communicate or to make sense of a bewildering environment
 - exacerbation or return of previous behaviours.
 - return to a long term memory that is now inappropriate
 - underlying neurological change,

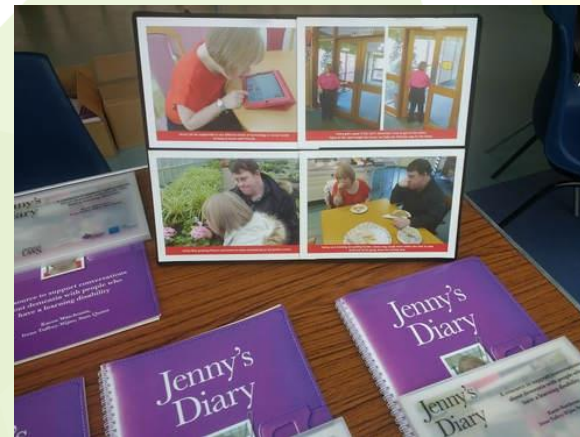
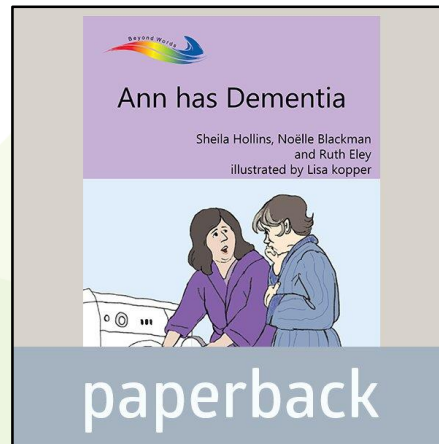
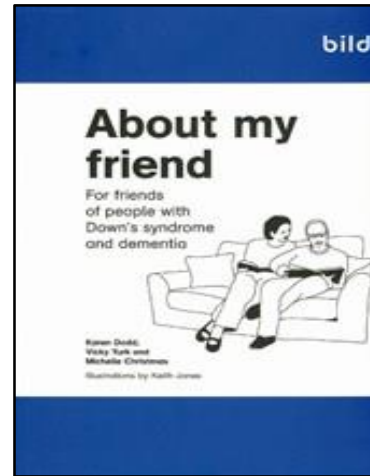
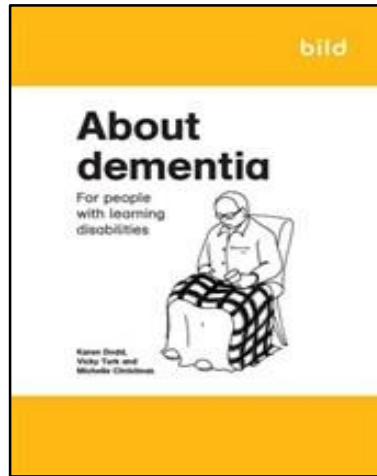
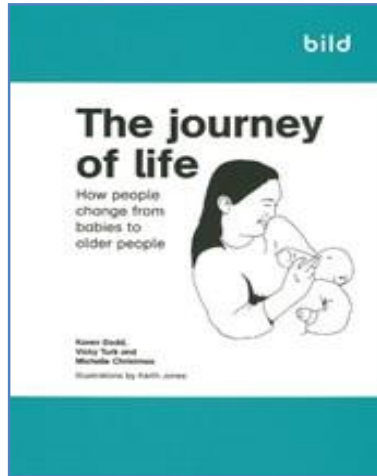
Managing behaviours

- Simple and practical solutions may work, e.g. a net to catch items thrown out of the window.
- Behaviours may reduce by reducing anxiety and stress. Introduce relaxation, avoid conflict and confrontation. Ask yourself: 'Does it matter?'
- Simple environmental alterations may alter the behaviour e.g. covering a mirror.
- Use usual methods of observing, monitoring, and understanding the function of the behaviour to decide on the best intervention, alongside thorough risk assessment and crisis management plans.

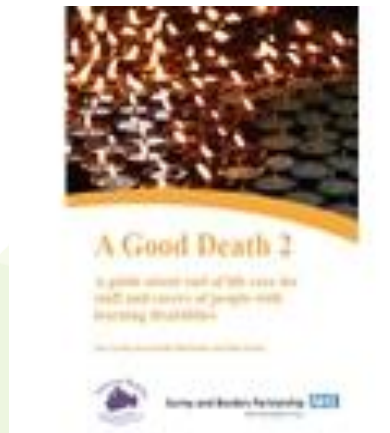
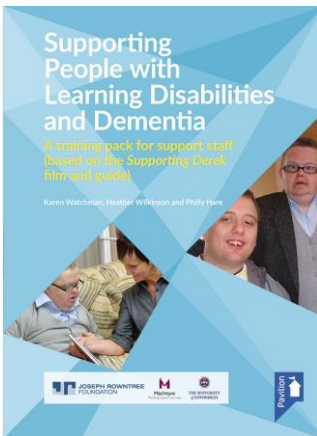
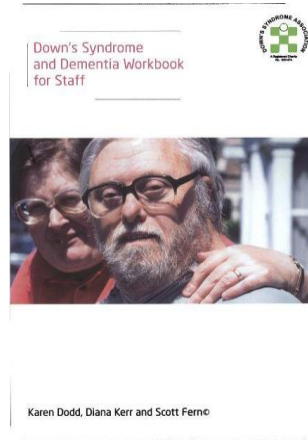
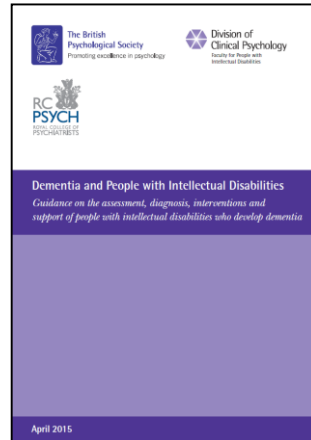
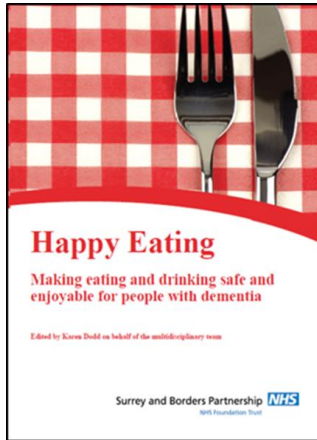
Example – agitation at night

- Sleep hygiene
- Increase daytime activity
- Relaxation strategies
- Environmental issues e.g. blackout curtains
- Timing of medications
- Staff checking and disturbing the person

Resources to use with people with LD



Resources for staff



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