NHS
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Supporting People with Learning Disabilities and Dementia

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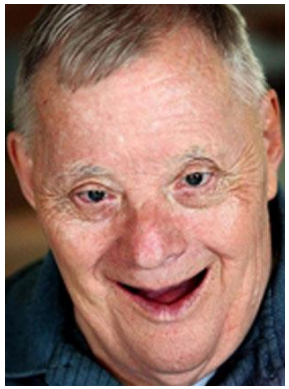

"Don't lose sight of the person behind the dementia…that person is still there. Maybe they're hiding behind a door which closes a little further each day. But until that door finally shuts tight at the moment of death, a narrow path to communication always remains open"

B Angell

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Growing Older with a Learning Disability

Learning Disabilities

Life Expectancy

Health Conditions

Risk of Dementia

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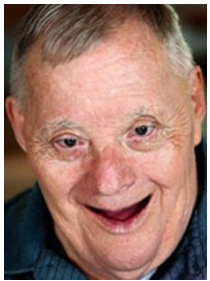

Things to think about …

Hidden Histories- Living with Disability. Family photo c.1920's

Alois Alzheimer

First reported association between Down's syndrome and DAT was made by Fraser and Mitchell in 1876

Plus

Increased life expectancy of people with learning disabilities alongside increased prevalence of dementia

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The scale of the challenge

850,000 people living with dementia in the UK

By 2025

over **one million** people could have dementia in the UK

By 2050

this figure will exceed **2 million**

Most people associate dementia with older people but there are more than 40,000 people in the UK under the age of 65 years who are affected by this condition.

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Growing Older with a Learning Disability (LD): What is known

- Ageing process for people with LD is similar to the general pop.
- Older adults with LD have increased incidence of health difficulties.
- People with LD will die approx. 15-20 years sooner than general population - Pneumonia (16%), Aspiration Pneumonia (9%), Dementia (4%)
- Potentially preventable causes of mortality that are relatively common and affect most groups of people with LD include aspiration pneumonia and seizures. (LeDeR, 2017)
- Onset of dementia in LD population earlier than general pop.
- People with Down's Syndrome are at a high risk of developing dementia with quick progression.

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INTELLECTUAL DISABILITIES & DEMENTIA

DS: DOWN SYNDROME • **ID:** INTELLECTUAL DISABILITIES
DAD: DEMENTIA IN ALZHEIMER'S DISEASE

Working with Intellectual Disabilities and Dementia in Advanced Stages

1 in **10** people between the ages of 50-65 with ID has dementia

Approx **50%** of people with DS will go onto develop a dementia

If you have ID you are **3** times more likely to have dementia

Every week **200** babies are born with ID in UK

In **88%** of people with DS and DAD epilepsy will be present

45% of the DS population now live to over 60

ID Increased risk gastric cancers

58% of cancers in ID population vs **25%** general population

DOWN SYNDROME:

Trisomy 21, Mosaic Down's Syndrome, Translocation Down Syndrome

Fragile X Syndrome

Prada-Willi Syndrome

Autism

(75% have a ID)

Asperger's Syndrome (no ID)

Epilepsy

SYMPTOMS

- Less insight into memory difficulties because of pre-existing cognitive function
- Often first changes are behavioural
- More disabled first signs can be apathy
- Language changes - Including makaton and sign where there are problems with motor skills
- Changes to motor skills
- Visual perceptual changes

DIFFERENT REALITIES

- Where orientation is appropriate use visual clues
- Validation, use knowledge of life history

DIAGNOSIS

- Baseline assessments required - DMR, DSDS, TSI
- Good recording essential
- Late onset seizures can indicate onset
- Require support to understand diagnosis

BARRIERS TO DIAGNOSIS

- Denial, fear of losing service
- 'Floor Effect'
- Diagnostic overshadowing
- Behaviour changes incorrectly attributed to ID

DS

- Baseline assessment recommended from age of 30
- Chromosome 21
- Brain of all people with DS show pathological change

WORKING WITH CHALLENGE

- Trigger - Environment or different realities
- Seen as consequence of dementia/ID rather than communication
- Education for peers
- ABC Charts
- Accident - Head injury - Chronic Subdural Haematoma – can cause dementia like symptoms

SENSORY

Cataracts and other sensory loss can appear earlier in DS population

DIFFERENTIAL DIAGNOSIS

- Poor Nutrition / Hydration
- Other Physical Causes - Heart Disease, Diabetes common in DS
- Medication Toxicity - Psychotropic medication
- Stress
- Sensory Loss - More ear wax because thinner inner ear tube
- Depression
- Abuse
- Thyroid
- Delirium
- Pain

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Behavioural & Psychological Symptoms of Dementia (BPSD)

Behavioural

- Sleep disturbance
- Wandering
- Agitation
- Aggression
- Excesses/deficits

Psychological

- Mood changes
- Depression
- Delusions
- Hallucinations
- Reduced insight
- Memory changes

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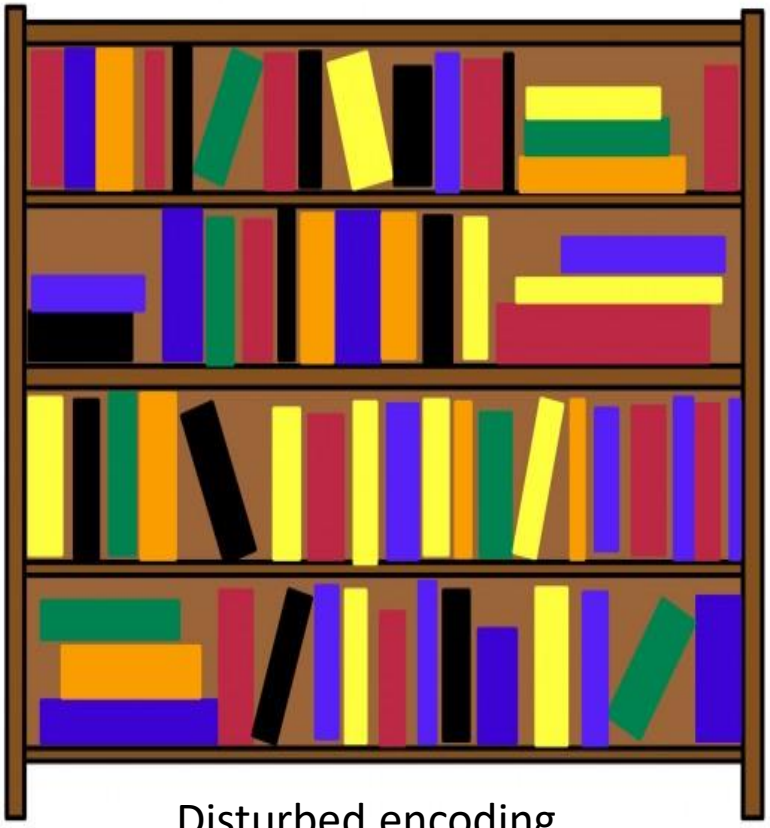
Dementia Signs: Bookcases and Dominoes



Disturbed encoding

Rollback Memory

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The Person Behind the Dementia

- Relating to the person before the dementia
- Tap into the expertise of the carer
- Listen to the message being conveyed
- Keeping the person at the centre of care and understanding

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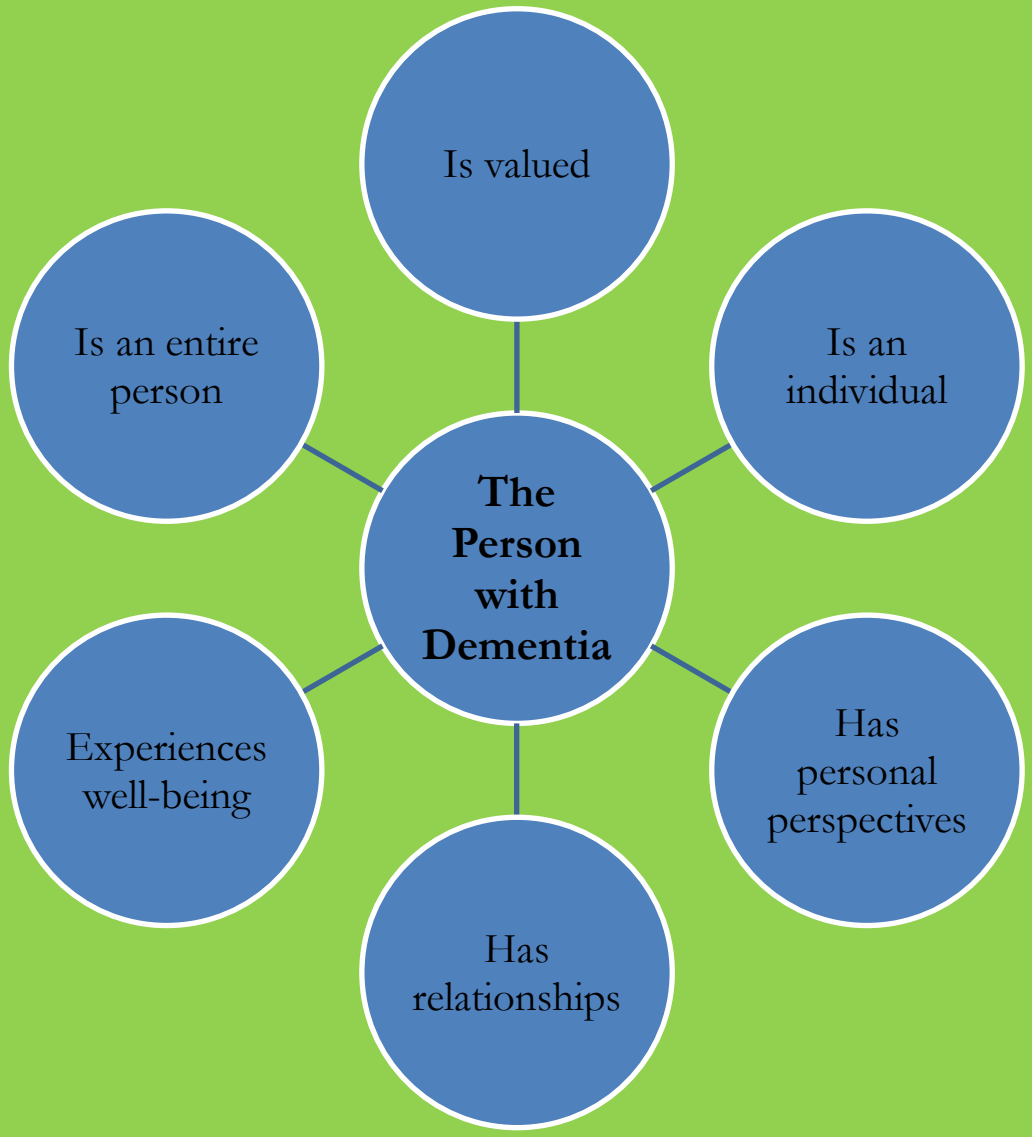
The Person is at the Centre



Work Alongside Carers

- To remember the person before the dementia
- To consider an alternative view of the situation
- To support information already obtained
- To offer a useful indication of how disabling an illness is or how behaviour affects other people
- To explore the awareness around individual's needs and difficulties across settings

Any ideas?

The curse of Ikea ??

Should we really be chucking out the chintz??

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Dementia friendly environments

- Most environments where people with learning disabilities live are not dementia enabled.
- Balance calm with stimulation so to minimise unhelpful stress
- Key principles
  - **Calm** – noise (internal and external), colour
  - **Predictable and make sense** – cues, signposting, no surprises
  - **Familiar** – homely, long term memory
  - **Suitably stimulating** – noise, views
  - **Safe and risk assessed** – access, stairs, hazards

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Philosophy of support & care

- Understand and know the person
- Understand dementia and its consequences
- Proactive approaches that predict ‘stressors’.
- Need to maintain the elements of usual daily living to retain skills for as long as possible
- Consider life story work and reminiscence approaches
- Ensure that the person with dementia has **failure free and individualised care that is consistent, with minimal stressors and ideally without time pressures**.

Supportive Interventions

Behaviour-orientated

- Functional analysis of behaviour of concern.
- Focus on understanding the behaviour as an expression of need(s)

Emotion- orientated

- Reduce distress, validate sense of self, enhance emotional wellbeing and support coping strategies.

Cognitive-orientated

- Help to maintain and optimise existing skills, abilities and independence.

Stimulation-orientated

- Meaningful, enriching activities to stimulate and engage an individual e.g. life story, reminiscence work.

(Kalsy-Lillico et. al., 2014)

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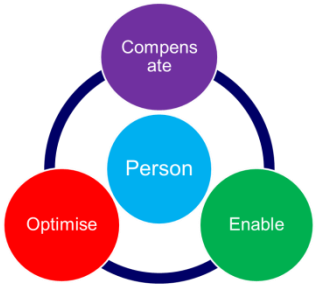

TRAINING ACROSS THE HEALTH & SOCIAL CARE SPECTRUM
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INTELLECTUAL DISABILITIES (ID) & DEMENTIA

INSPIRED BY KAREN WATCHMAN - Caroline Bartle 2014

PATHOLOGY

The trigger & progression of dementia may differ in ID. Significant factors in DS: the presence of the gene APP may lead to the over production of the protein AB associated in Alzheimer's, & frontal temporal lobes are likely to be primarily affected. First symptoms observed are often a change in character, perhaps not because the condition is progressed but because the pathology differs.

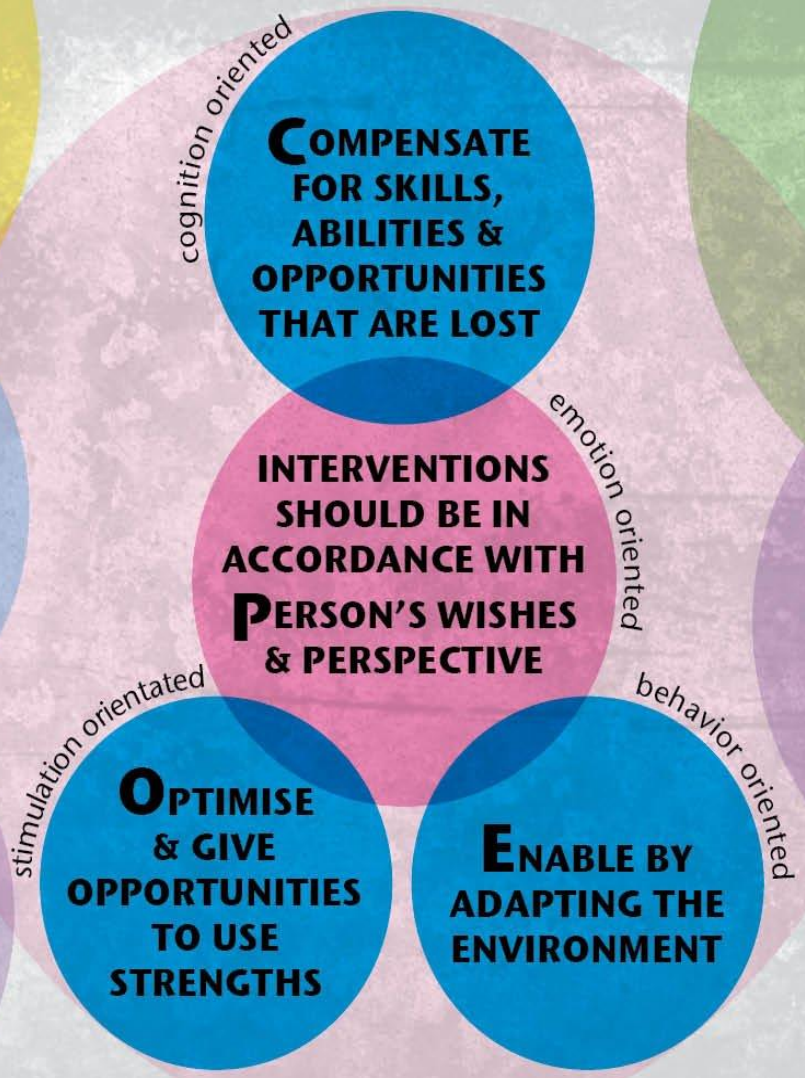
DIAGNOSTIC

Thyroid & sensory problems are often overlooked. There is a lack of shared diagnosis with the individual concerned, possibly because of labelling.

MEDICATION

Little research exist on the use of anti-dementia drugs in ID. These drugs are metabolised through the liver & their effectiveness could be influenced by any other medication. Capacity & consent need to be considered in the use of medication.

COPE MODEL WITH A FRAMEWORK FOR PSYCHOLOGICAL INTERVENTIONS (KALSY-LILLICO ET AL 2012)



NON-PHARMA INTERVENTIONS

To cope with care giver demands often medication is first line treatment where as non-medical could be effective, such as: environmental design, training for support staff, multi-sensory, assistive technologies. People with coexisting physical & mental conditions will experience the dementia differently. To develop perspective of dementia & ID try ***GOLD*** group.

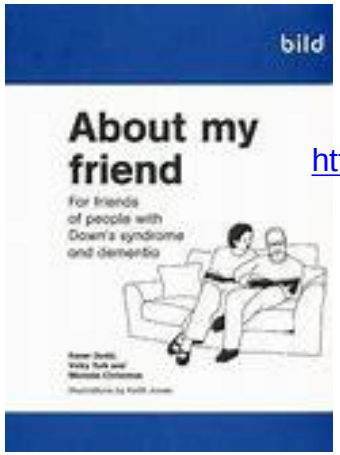
PROACTIVE SERVICE PLANNING IS KEY IN ID

We need a proactive versus reactive approach. We know that there is a higher risk of dementia in ID population so let us start planning to prepare our services now.

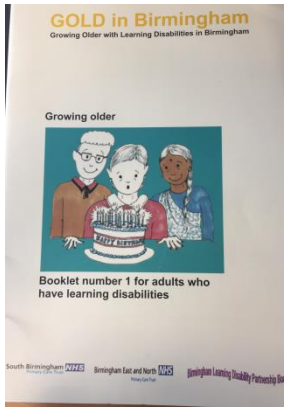
Meeting changing needs

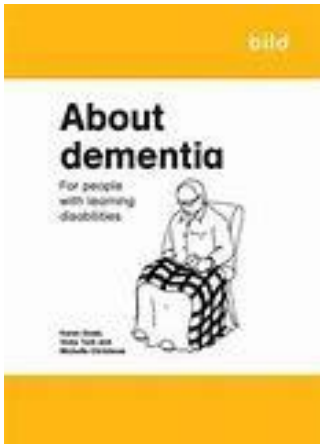
- Emphasis of care changes from enabling the person to maintain their skills with support to increasingly taking on tasks for the person with dignity and respect.
- **Early stages** - reminding the person of the day, time, place; simplifying routines and reducing choices; introducing memory aids such as diaries, timetables and objects of reference; simplifying communication, and using additional cues/prompts .
- **Mid stages** - care changes to preserve abilities for as long as possible using techniques of reminiscence, identifying favourite activities and strengths, finding failure-free activities.
- **End stages** – health monitoring becomes essential. Attention to weight, adequate nutrition and hydration, physical health including epilepsy, continence, pain and mobility are all vital.

Accessible resources



https://www.changepeople.org





www.easyhealth.org.uk

inclusivefilms.org

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Be the person that made that difference

- Access training materials on dementia
- Access specific resources relating to dementia and people with Down's Syndrome for the person and their caregivers
- Broaden knowledge across the whole life course. Ageing well and supporting people with dementia, including end of life care with dignity.
- Access appropriate assessment and investigations
- Be calm and relaxed around the person and give more time to process information and experiences
- Try to use regular carers, familiar faces and places
- Promote a healthy lifestyle '***healthy heart healthy brain***' reduce the likelihood of vascular dementia
- Be sure that you look at the whole person not just the diagnosis

"Be my friend, for I need one,
but do not be my manager.
And remember me,
as my life and identity erode,
as a person, not a case"

J Ossofsky 1993

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