Birmingham Community Healthcare NHS Foundation Trust

Ageing, Dementia and People with Learning Disabilities

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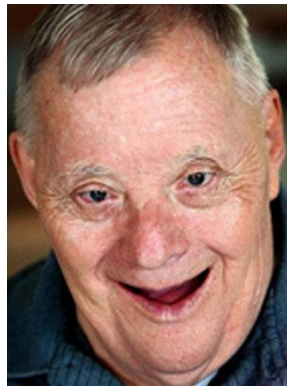
24th September 2019



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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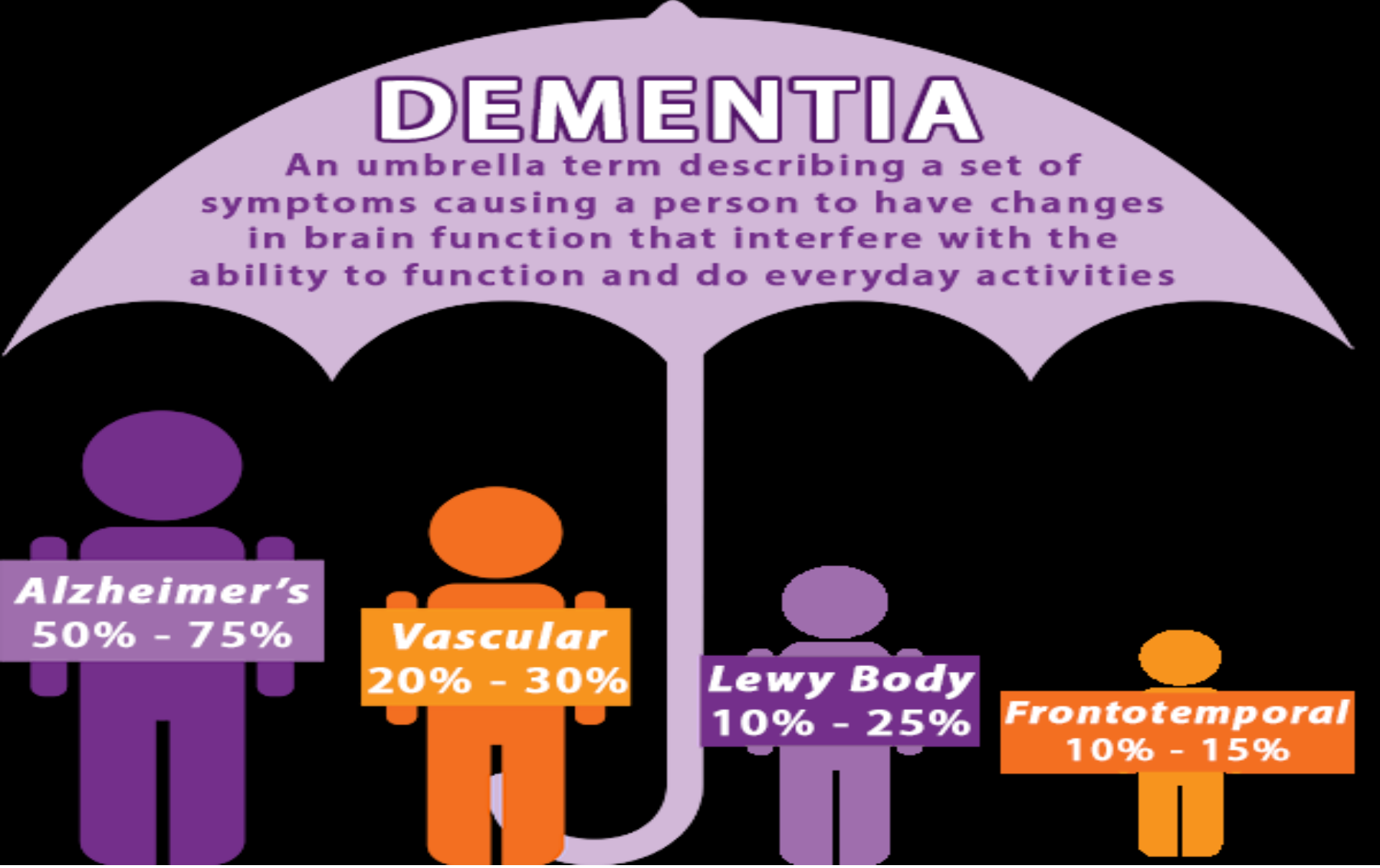

https://fundamentalsofnursingblog.wordpress.com

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Growing Older with a Learning Disability

Learning Disabilities

Life Expectancy

Health Conditions

Risk of Dementia

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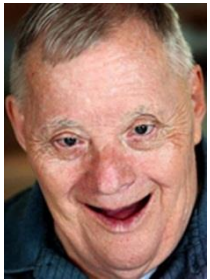

Things to think about …

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

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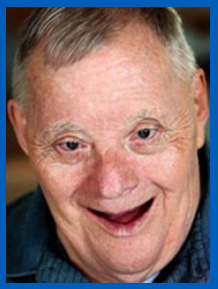
Growing Older with a Learning Disability



- Ageing process for people with a LD is similar to the general population. Research has shown that older adults with a LD have increased incidence of health difficulties.
- Causation of dementias are being researched with genetic and neuropathological studies with people with LD and those with Down Syndrome
- Onset of dementia in the LD population tends to be earlier than in the general population.
- People with Down's Syndrome are at a high risk of developing dementia and the condition progresses more quickly.
- Potentially preventable causes of mortality that are relatively common and affect most groups of people with LD include aspiration pneumonia, seizures and dementia (LeDeR, 2017)

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

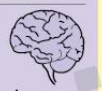
- Baseline assessments required - DMR, DSDS, TSI
- Good recording essential
- Late onset seizures can indicate onset
- Require support to understand diagnosis

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

What changes might be reported?

- Behavioural and/ or personality changes
- Decline in daily living and/or personal care skills
- Decline in mobility
- Withdrawal and disengagement in usual interests
- First onset or change in presentation of epilepsy.
- Swallowing difficulties: Dysphagia

Challenges in Recognition and Assessment

- Assessment tools are usually designed for people who had a previously intact level of cognitive function
- Not always any single / baseline documentation of previous functioning
- Early memory loss and communication problems often masked initial changes attributed to LD
- Differential diagnosis & assessments
- And the course of these changes….

The course of dementia …

Benidorm Aquapark

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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.

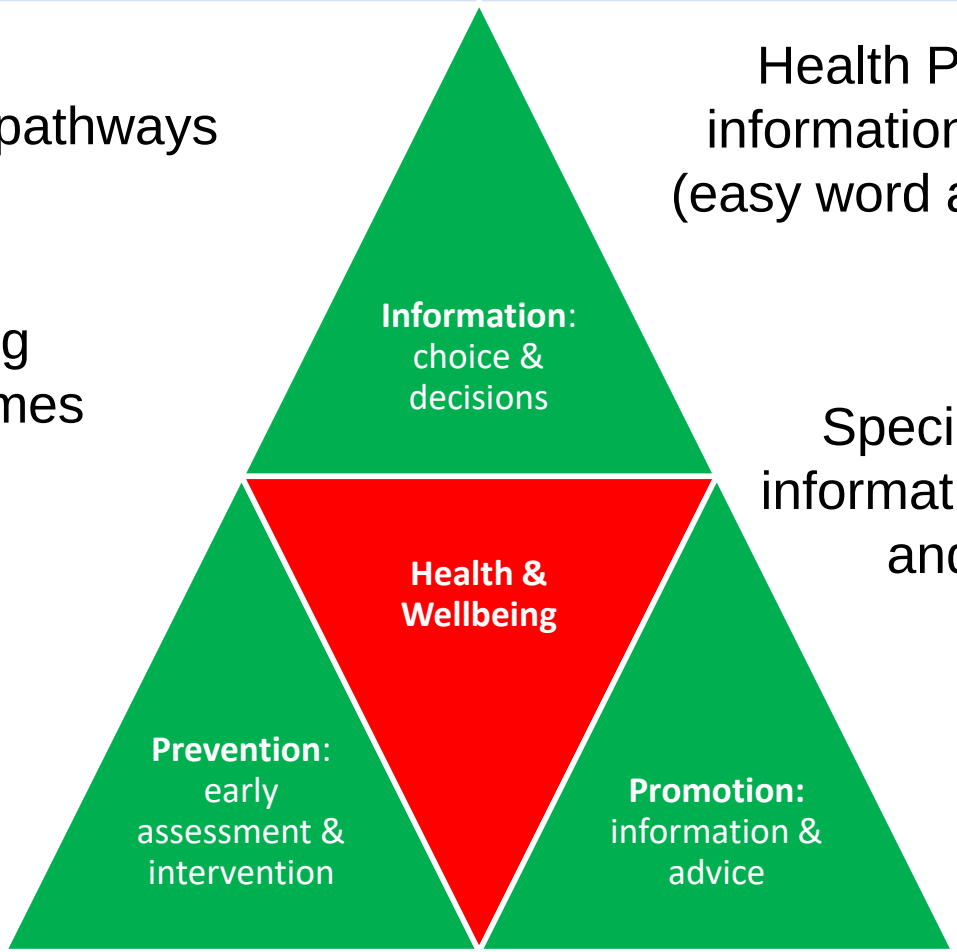
Birmingham Response
Working together

Care pathways

Training programmes

Ageing well groups

Service re-design



Health Promotion information resources (easy word and pictures)

Specialist health information, guidance and advice

Environmental audits

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Birmingham Response
Working together

- Health Promotion information resources (easy word and pictures)
- Training programmes
- Environmental audits
- Ageing well groups
- Service re-design
- Care pathways…….

Impressive Results!

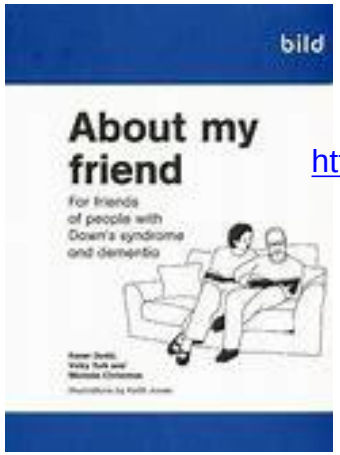
The British Psychological Society
Promoting excellence in psychology

CareQuality Commission

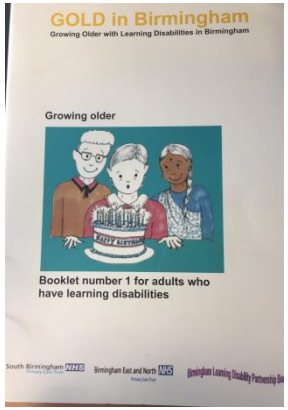
NHS West Midlands Healthy Communities

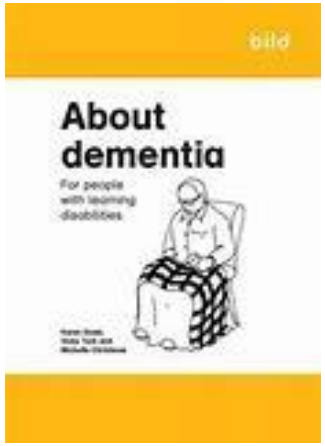
The National Learning Disabilities Awards

Accessible resources



https://www.changepeople.org





www.easyhealth.org.uk

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Interventions

Four orientations of psychological interventions that will support pharmacological interventions:

Behaviour-orientated

- Functional analysis of behaviour of concern.
- Focus on understanding the behaviour as a form of communication

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, reminisce work.

(Kalsy-Lillico et. al., 2012)

Any ideas?

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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

Philosophy of care

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

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.

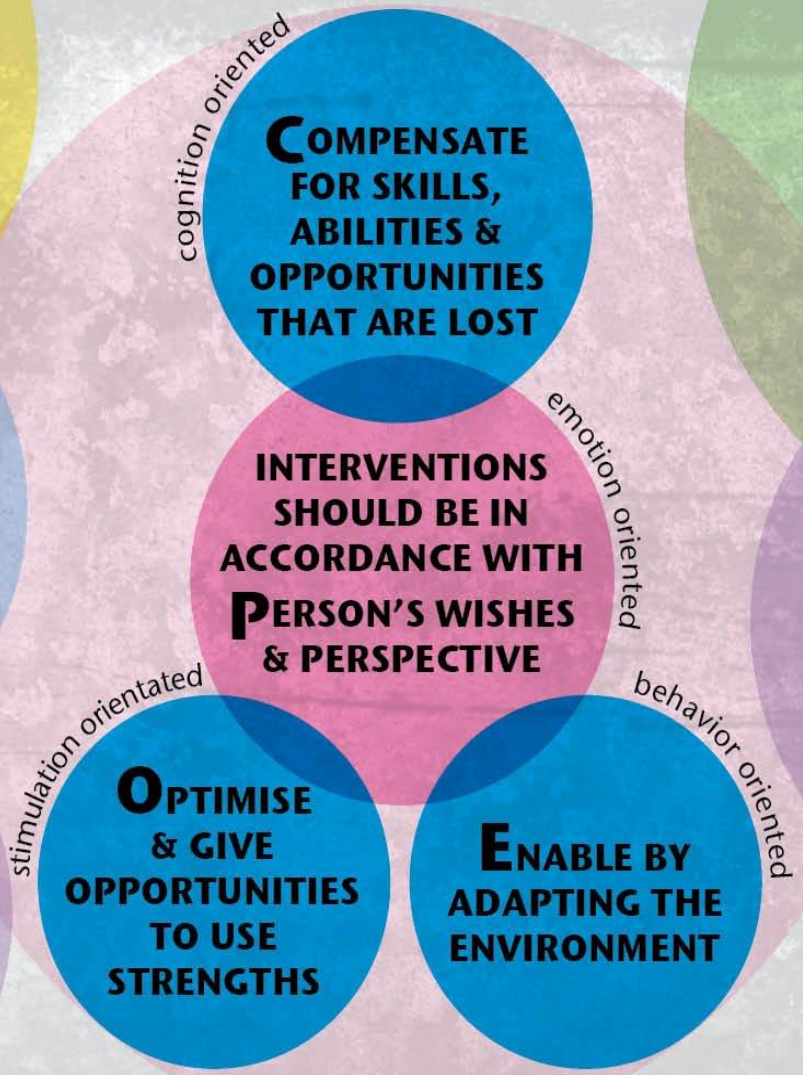
DIAGNOSTIC

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.

Ageing well …….

Active ageing for people with learning disabilities

inclusivefilms.org

www.inclusivefilms.org

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Be the person that made that difference

- Access e-learning materials on dementia
- Access specific resources relating to dementia and people with Down's Syndrome
- Be calm and relaxed around the person and give more time
- Try to use regular carers, familiar faces
- Promote a healthy lifestyle '***healthy heart healthy brain***' reduce the likelihood of vascular dementia
- Access appropriate assessment and investigations
- Broaden your knowledge across the whole life course. Ageing well and supporting people with dementia, including end of life care with dignity.
- Public Health England has developed an online resource called All Our Health
- Be sure that you look at the whole person not just their diagnosis

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thank you

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