



# **Dementia and People with Learning Disabilities Charter**

**Useful resources**

**Introduction**

**The National Strategy**

**The Outcomes wanted**

## Useful resources:

### **Down's Syndrome Association**

[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

### **BILD**

[www.bild.org.uk](http://www.bild.org.uk)

### **BPS / RCPsych Joint Guidance on Assessment, Diagnosis, Treatment and Support of People with Learning Disabilities and Dementia**

[www.dcp-ld.bps.org.uk/document-download-area/document-downloads.cfm?file\\_uuid=264C29FC-D1BE-428A-4EA5-857A550796F7](http://www.dcp-ld.bps.org.uk/document-download-area/document-downloads.cfm?file_uuid=264C29FC-D1BE-428A-4EA5-857A550796F7)

### **Quality Outcome Measure for Individuals with Dementia (QOMID)**

[http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info\\_home.cfm](http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm)

### **Living Well with Dementia Easy Read Guidance**

[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_094052.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094052.pdf)

### **ihal Improving Health and Lives**

[www.improvinghealthandlives.org.uk/](http://www.improvinghealthandlives.org.uk/)

## Introduction

**People with learning disabilities in general and people with Down's syndrome specifically, have a higher risk of developing dementia and at a younger age than people in the general population.**

The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.

## Introduction

The National Dementia Strategy: Living well with dementia (DH, 2009) applies equally to people with learning disabilities.

**The strategy has three key principles:**

- 1** - Improved awareness and understanding of dementia and removal of the stigma that surrounds it.
- 2** - Early diagnosis and intervention.
- 3** - Improving the quality of care for people with dementia by developing a range of services for people with dementia and their carers which fully meets their changing needs over time.

It is vital to remember that dementia is a progressive illness that requires a constant re-evaluation of the care that is provided to ensure that it is meeting the person's changing needs.

# National Dementia Strategy

- 1** Improving public and professional awareness and understanding of dementia.
- 2** Good-quality early diagnosis and intervention for all.
- 3** Good-quality information for those with diagnosed dementia and their carers.
- 4** Enabling easy access to care, support and advice following diagnosis.
- 5** Development of structured peer support and learning networks.
- 6** Improved community personal support services.
- 7** Implementing the Carers' Strategy.
- 8** Improved quality of care for people with dementia in general hospitals.
- 9** Improved intermediate care for people with dementia.

# National Dementia Strategy

- 10** Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.
- 11** Living well with dementia in care homes.
- 12** Improved end of life care for people with dementia.
- 13** An informed and effective workforce for people with dementia.
- 14** A joint commissioning strategy for dementia.
- 15** Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
- 16** A clear picture of research evidence and needs.
- 17** Effective national and regional support for implementation of the Strategy.

## THE OUTCOMES wanted

- 1** **The person** will experience support which is underpinned by comprehensive person centred planning based on their own wishes, their capacity (maximising their decision making, wherever possible), and their needs and history.  
**The support plan needs to include:**
  - person centred plan • health care plan • communication
  - passport • life story book • advanced directives
  - end of life planning.
- 2** **The person** is supported to take appropriate risks that enhance their opportunities to live an independent, fulfilled life wherever possible, and is supported by people who take positive action to ensure that the person still has a range of fulfilling life experiences as the dementia progresses.
- 3** **The person's** human rights are fully respected by ensuring that there is full compliance with the current legislation e.g. **Mental Capacity Act** and **NICE** guidelines particularly in relation to prescribing:
- 4** **The person** experiences consistency of approach in all settings, being supported by familiar people and with the amount of care adapted promptly to meet their changing needs.

## THE OUTCOMES wanted

- 5** **The person** experiences calm and constructive interaction with family, staff and friends, who adapt the amount of language used and use symbols and pictures as required, with no confrontation; no time pressures; and validation of roll back memories.
- 6** **The person** receives explanations about their dementia and reassurance about the effects of the disease as appropriate to their wishes and level of ability. They are reassured about their condition by the way people interact both verbally and non-verbally.
- 7** **The person** is oriented to time and place through approaches that are appropriate to their level of ability including the use of appropriate cues and aids e.g.daily picture timetable, picture menus, picture staff rotas.
- 8** **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. Care is delivered in a dignified and respectful manner.
- 9** **The person** continues to access and enjoy familiar social, leisure, work, respite and recreational activities in their local community through flexible supports.



## THE OUTCOMES wanted

- 10** **The person** lives and spends their time in environments that are familiar to them and have all the necessary aids/adaptations to help them find their way around and meet their needs, and minimises risks of falls.
- 11** **Behavioural** issues are minimised by ensuring that the person experiences support that understands the context of their behaviour, responds with compassion and avoids confrontation.
- 12** **The person's** physical and mental health needs are met promptly and appropriately including attention to: Pain recognition and management, thyroid function, vision, hearing, blood pressure, diabetes and mental wellbeing. Medication is prescribed appropriately and reviewed regularly.
- 13** **The person's** needs are met by people from providers in primary care, secondary care, social services and voluntary sector who have a good understanding of the needs of people with dementia, and who work well together with the person and their families.
- 14** **The person** enjoys excellent support to maintain good nutrition and hydration, mobility and continence with appropriate aids and adaptations in place and prompt access to an appropriate clinician when difficulties are recognised.

## My Notes & Contacts:

	Name	Email	Tel
Best Interest Assessor			
MCA Lead/DoLs			
Independent IMCA			
Learning disabilities Liaison/Lead			
Local Authority Adult Safeguarding Lead			
Local Authority contact			



## My Notes & Contacts:



This set of cards was produced by the  
NHS Strategic Health Authority  
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