

Need2Know

Hidden in Plain Sight – Dementia and Learning Disability

Easier to read summary



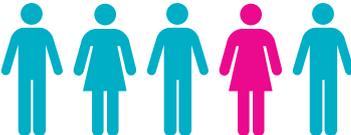
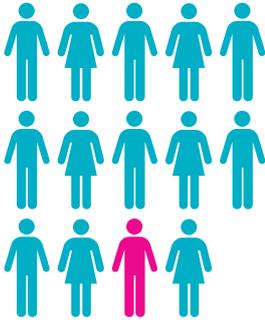
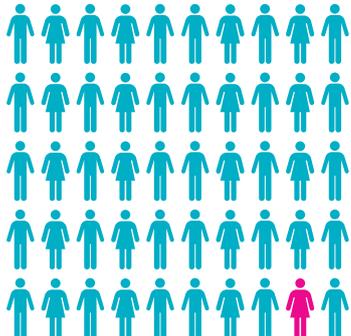
Mental Health
Foundation

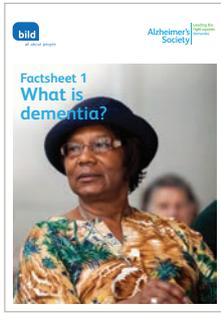


foundation for
people with
learning disabilities

People with learning disabilities have the same rights as everyone else. It is wrong for their rights and needs to be ignored. Government, commissioners, care managers, doctors, staff, providers of services, ALL must offer the best support for people with learning disabilities.

This Need2Know is about Dementia

	<p>Dementia is a disease that effects the brain.</p>
	<p>People with learning disabilities and people with Downs syndrome are more likely to get dementia.</p> <p>1 in 5 people with a learning disability over 65 years-old will develop dementia.</p>
	<p>1 in 14 people <u>without</u> a learning disability over 65 years-old will develop dementia.</p>
	<p>People with Downs syndrome get dementia earlier than everybody else.</p> <p>1 in 50 people with Downs syndrome will develop dementia during their 30's.</p>



If you are worried about dementia, talk to your doctor. Please remember that not everyone with a learning disability will get Dementia.

Read this easy-to-read **factsheet** from the Alzheimer's society on what is Dementia.



For Policy Makers

People with learning disabilities are more likely to get dementia. However, they are not included in policy about dementia.



Policies do not include people with learning disabilities in their guidance.



The government sees dementia and ageing as important priorities.

People with learning disability must also be included.



Commissioners (people that pay for services locally) need to make sure that people get the right support from when they find out they have dementia and into old age.



Commissioners need to understand that dementia gets worse as the individual gets older.

Therefore, commissioners need to supply extra money to help the individual continue living a good life.



All **staff in health and social care** should work together to make sure that people get the right support.

This support needs to start when the individual finds out they have dementia and as it gets worse.



Money from health services (continuing health care funding) is not offered early enough.

Commissioners need to find other ways to increase the support needed. For example, paying for one-to-one support or hiring night staff.



People need good services at each stage of dementia to ensure a good quality of life.



All staff involved in assessment, diagnosis, and care need to have good training.



Support and end of life care needs to be planned in a person-centred way.



It is important to diagnose dementia early in order to find out the individual's wishes and plan for when the dementia gets worse.



The person's home must be dementia-friendly and let them live as they want.



Care staff must understand dementia, and management must be flexible and person-centred.



Care management must meet with the person often to make sure that they get the support they need as their needs change.



Everyone involved in assessment, diagnosis, and care must work together to ensure the best support.



What would good support look like?

- Get to know the person and be person centred
- Include everyone who knows the person well
- Develop a person centred plan and a life story book
- Provide informed choices
- Support the person to share their voice and live the life they want
- Support the person to stay in their home and live with people they like
- Focus on the person not on the Dementia
- Keep people informed as they might worry about getting dementia



This paper has been produced by the Foundation for People with Learning Disabilities, which is part of the Mental Health Foundation.

It is written in partnership with the Dementia Action Alliance (DAA), Voluntary Organisations Disability Group (VODG), MacIntyre Charity, and Surrey and Borders Partnership NHS Foundation Trust.

It incorporates the British Psychological Society (BPS) commissioners' guide, which we have been given permission to include.

Please download the report and Easier to Read summary here:

mentalhealth.org.uk/dementialearningdisability

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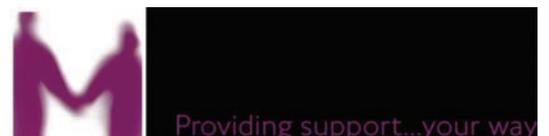


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