

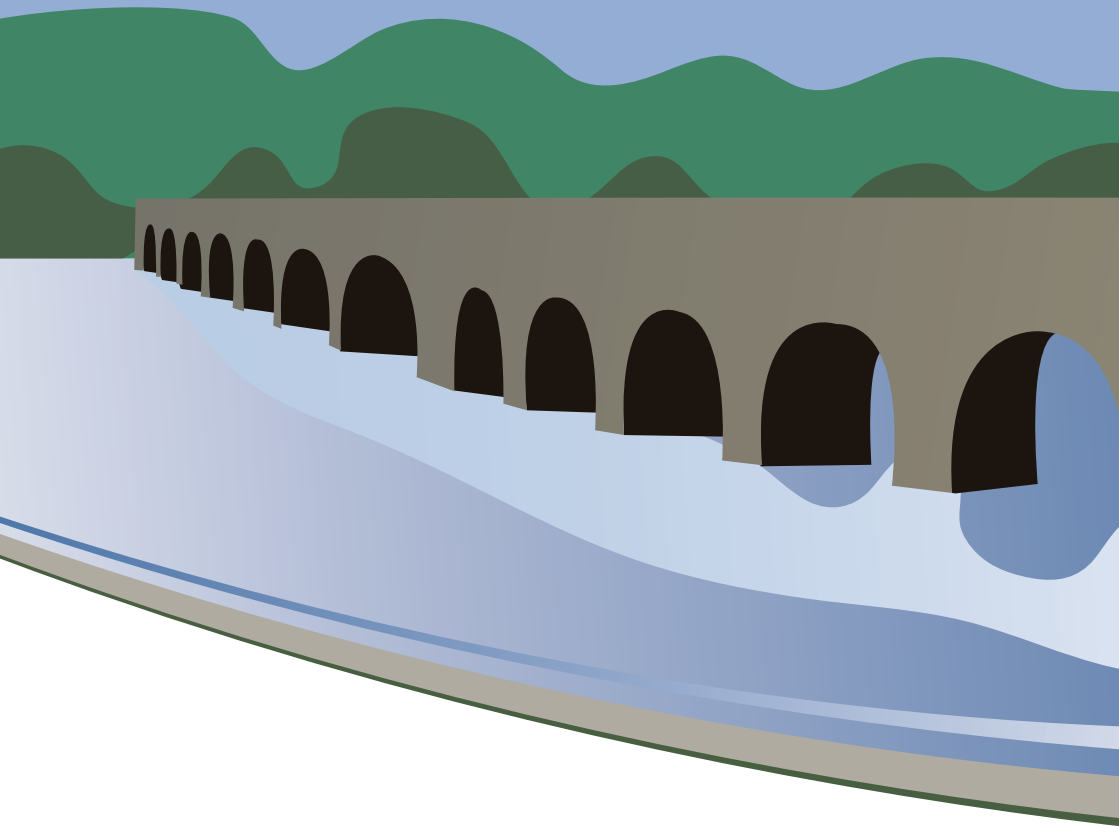
Alzheimer's
Society

Leading the
fight against
dementia



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

www.cymru.gov.uk



National Dementia Vision for Wales
Dementia Supportive Communities

Introduction

In Wales, we are justifiably proud of the communities we have built, just as we are proud of our citizen-based approach to delivering public services. We know that the vast majority of people who experience dementia wish to live near their family and carers. They wish to remain within their communities for as long as possible and in the homes of their choice. It is within this context that we must tackle the challenges that dementia brings.

The rising numbers of people with dementia in Wales is a trend which is common across the world. There are some challenges that are specific to Wales, including the need to address the impact on rural communities, as well as the Welsh Language which is especially important for those who may only understand or be able to communicate in their first language as their illness progresses.

Impact in Wales

By 2021, the number of people with dementia across Wales is projected to increase by 31% and by as much as 44% in some rural areas

What we also know from people with dementia, their carers and families is that if people receive an early diagnosis of dementia and are given access to appropriate information, support and care, it is possible to live well with dementia. Our ambition must be to ensure that people at whatever stage of the condition are given the best chance to live well and to be as active a part of family and community life as they can.

We must do all we can to ensure that people who need treatment receive it at the right time and in the right place. We need to plan services to take into account the needs of people who live in rural and urban settings, and ensure that language and cultural needs and preferences are catered for.

It is a priority therefore that we develop more closely integrated services, more comprehensive programmes of care and a greater awareness and understanding of the needs of people with dementia and those close to them, such as their families, friends and carers.

Wales' response will also be firmly rooted and grown from its communities. Our long term vision is to create 'Dementia Supportive Communities'. To do this requires a change in attitudes and behaviours towards dementia at all levels of society, which reflect the challenge of demographic change and the impact of dementia.

It requires a society in which people with dementia, and those who care for them, are treated with the dignity and respect they deserve, along with the help and support they need.

There has been a significant amount of work undertaken in Wales, including a full public consultation, to identify the actions that are required to deliver better quality of life for people with dementia in Wales immediately. Four priority areas have been identified for improvement:

1. Improved service provision through better joint working across health, social care, the third sector and other agencies;
2. Improved early diagnosis and timely interventions;
3. Improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy;

4. Improved training for those delivering care, including research.

The Welsh Assembly Government further demonstrated its commitment to improving dementia services in July 2010 by announcing that additional funding of £1.5 million each year would be available to support and implement the actions identified.

In reaching this point, there has been a great deal of collaboration with stakeholders, and it is essential that this partnership working continues in delivering this vision.

This document sets out not only why there is a need for improvements but what has already been done to address this need. The document also sets out how we can realise our vision going forward by improving dementia services in Wales.

Dementia Supportive Communities

Communities which have the capacity to support people affected by dementia so they can enjoy the best possible quality of life

How to Use this Document

As well as setting the vision for those delivering dementia services in Wales, this document is also intended to be of practical use for those who receive services and will form part of an information pack given to individuals at the point of diagnosis.

The pack will contain:

- **Vision document**

This document, which sets out the vision for dementia services in Wales.

- **Information booklets**

Booklets aimed at those diagnosed with dementia and their carers, intended to give more detailed information, which will be of practical use for people with dementia and their carers.

- **Contact and support information**

Details of local support groups and contacts provided by the relevant Local Health Board and Local Authority working in partnership.

What is Dementia?

Dementia' is caused by diseases of the brain and has symptoms which include the gradual loss of memory, reasoning and communication skills.

There are different types of dementia, with the most common being Alzheimer's Disease and vascular dementia.

Dementia is not a natural stage in the ageing process but a progressive illness that tends to affect the individual in a gradual manner, moving from initial memory problems to the loss of the essential elements of mental functioning. In the later stages of dementia, people can be very vulnerable because of its effects.

However, there is considerable evidence, in particular from people with dementia and their families, that where people receive an early diagnosis of dementia and are helped to access information, support and care, people are often able to adapt to living well with dementia.

The symptoms associated with dementia can be managed and lives can be improved if it is identified as early as possible. Those with dementia and their families can also be helped by having access to appropriate information and responsive services. It is also very important that we make our society, and in turn our communities, aware and supportive by working to remove any stigma associated with the condition.

World Projection

Expected to be over 115 million people with dementia by 2050

Anyone in society can be affected with dementia, irrespective of gender, ethnicity or class. It can affect adults of working age as well as older adults, and people with learning disabilities are a group particularly at risk. It must also be noted that many people with dementia will also have other underlying health needs and conditions. The Alzheimer's Disease Society reports that;

- **Older People:** Dementia is more common as people age. One in 14 people over 65, one in 6 people over 80, and one in three people over 95 has a form of dementia;.
- **Learning Disability:** Studies have reported increased rates of dementia in people with Downs syndrome.

- **Younger Onset Dementia:** The causes of early onset dementias (i.e. under 65 years) include Alzheimer's Disease, dementias relating to alcohol misuse and conditions such as Parkinson's Disease.

The Challenge of Dementia – the Facts

There are currently just over 37,000 people living with dementia in Wales, and it is important to note that the effect on the individual is different in each case. People who have dementia are not alone and they and their carers can still have a good quality of life.

This is not just a problem affecting Wales; the most up-to-date statistics show that the numbers of people with dementia are rising across the UK and the world.

In the UK there are an estimated 750,000 people with dementia, and this is projected to rise to over one million by 2025.

Worldwide, there are currently estimated to be over 35 million people with dementia, and that number is expected to almost double every 20 years in the future.

Financial Cost of Dementia

Although it is recognised that family carers of people with dementia save the UK over £6 billion a year, the current financial cost of dementia to the UK is estimated to be over £20 billion

The Dementia Vision in Wales

Much work has taken place in Wales recently to identify the priority areas that need to be addressed to improve the lives of those with and affected by dementia.

Wales needs a long-term vision to ensure we can best meet the challenge of an increasing number of people living with dementia within our population.

Our vision is to create Dementia Supportive Communities. Wales will work to strengthen communities, creating a key resource for people affected by dementia at local and national level. The objective being that over time, building on local improvements from the grass roots up, a network of local dementia supportive communities will create a national dementia supportive community.

As well as improving and developing health and social care services to deal with the dementia challenge, support will also need to be provided by communities, by the third sector, and public and independent sector organisations. Crucially, all services will need to work together in an integrated way, adding value to each and enabling services to be tailored to the individual needs of people affected by dementia.

The key outcomes to developing Dementia Supportive Communities within Wales are that:

- The community articulates the voice of people affected by dementia;
- The community is consulted and listened to;
- Where services are available, they are accessible and responsive to the needs of the community they seek to serve;
- People with dementia are included in community activities and they and their carers are supported by that community.

Our Commitments

The Welsh Assembly Government has made a commitment to make immediate improvements to dementia services in Wales by taking forward the priority actions that have been identified and delivering the following commitments:

1. Our Commitment...to improve services by:

- employing dementia clinical co-ordinators to support those diagnosed with dementia;
- creating a new young onset dementia service for Wales;
- progressing our high level national dementia targets.

2. Our Commitment...to improve information by:

- developing information packs for those diagnosed with dementia;
- creating a dedicated dementia information helpline for Wales;
- extending the Welsh Assembly Government's Book Prescription Scheme to include dementia care.

3. Our Commitment...to raise awareness by:

- including dementia in other Welsh Assembly Government health campaigns;
- ensuring that dementia issues are communicated to health colleagues in other disciplines through networks and bulletins;
- updating appropriate voluntary organisations funded by the Welsh Assembly on dementia issues.

4. Our Commitment...to improve training by:

- developing training packages to be delivered to health and social care professionals and local authorities on dementia;
- creating training packages (learning resources) to support carers;
- providing additional training to Community Advice Listening Line staff.

5. Our Commitment...to support research by:

- recognising the importance of dementia research and continuing to support research into dementia cause, cure and care;
- offering funding opportunities to researchers wishing to undertake dementia research.

6. Our Commitment...to work towards our long term vision by:

- establishing a high level dementia group to drive change in dementia services;
- improving care to those with a dementia on general wards;
- ensuring that bilingual provision of services for those diagnosed with dementia is planned for.

Achieving Success

Having identified the challenges and the action that is required to improve dementia services in Wales, along with the additional financial investment that has been made despite the current financial climate, the Welsh Assembly Government is committed to improving dementia services in Wales, both now and into the future.

It is vitally important that organisations and communities across Wales work together to address the priorities identified, and put the national vision into practice. The Minister for Health and Social Services established the Mental Health Programme Board to ensure that mental health services are high quality and provide the best value for money. It is this Group that has been tasked with ensuring that NHS Wales, local government and the voluntary sector work together in an efficient and effective way to deliver coordinated services.

The Welsh Assembly Government will continue to provide leadership to support this work and implement the vision. This work will be regularly reviewed and reported to Ministers to make sure improvements are being made.

Some Helpful Services, Websites and Phone Lines

Age Cymru

Tel: 0800 1696565

www.agecymru.org.uk

Alzheimer's Society

Tel: 02920 480593

www.alzheimers.org.uk

Wales Dementia Helpline

Tel: 0808 1410043

Text – 81066

www.dementiahelpline.org.uk

Crossroads Care

Tel: 0845 4500350

www.crossroads.org.uk