

Bite Size Dementia Diagnosis Rates Communication Resources

CHAPTER 2 – Dementia Diagnosis
Raising the Awareness Resource

Caring

Understanding

Important Possibility

Resourceful



Memory Assessment Services

Empowering Hope

Rewarding

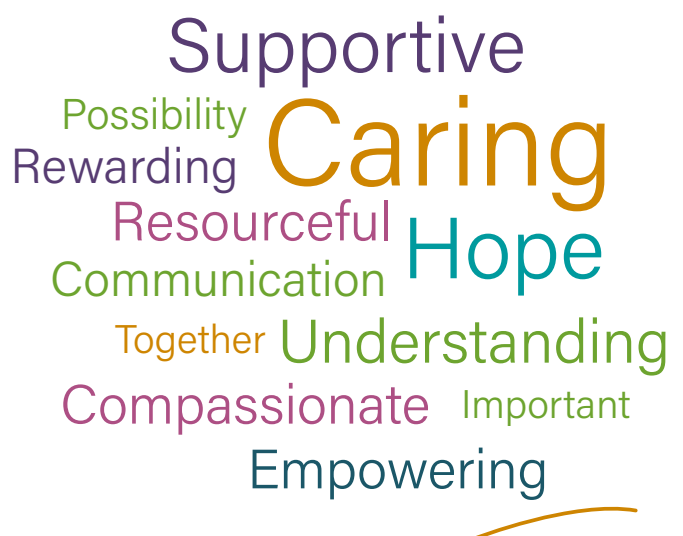
Communication

Supportive

Contents

Introduction	4
2.1 Engagement and Communication Activity	4
2.2 The Context and Aims	4
2.3 Implementation and Evaluation	7
2.4 Other resources from partners	7
Appendix 1 Dementia: Why diagnose? So what?	10
Appendix 2 Dementia? Benefits of a timely diagnosis	12
Appendix 3 Measurement Guidance	14

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Rewarding
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Communication
Together
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Empowering
Caring
Hope
Understanding
Important



Introduction

2.1 Engagement and Communication Activity

"What is this... and **Who** is it for?"

Improvement Cymru has worked with Memory Assessment Services (MAS), organisations and people living with dementia to create communication improvement activities and resources. These resources have been developed for the MAS Regional Workstream, MAS Team Leads and General Practice Managers, teams and partners including the Alzheimer's Society Cymru.

Chapter 2 focuses on Dementia Diagnosis and raises awareness of the supporting workforce resources available to the workforce, people with dementia, carers and the public.

2.2 The Context and Aims

"Why Implement... this **Activity**?"

The Dementia Action Plan (2018) states we need to increase the Dementia Diagnostic Rates in Wales by 3% annually from the recorded low rate of 53%. In comparison to the other three nations, the Wales dementia diagnostic rate was the lowest recorded, significantly 20% below Northern Ireland's 73% dementia diagnostic rate (2017/2018).

The data suggests that there is possibly 46.9% of people living in Wales who have not received a formal dementia diagnosis and therefore may not have received access to appropriate risk reduction, preventative, skill maximising and cognitive health wellbeing interventions, that include psychosocial and appropriate pharmacological care and support.

Data from 2019-20 from the QAIF (Quality Assurance Improvement Framework) shows the following trends:

Quality Assurance and Improvement Framework (QAIF) 2019-20

Estimated number of undiagnosed people aged 65 or over with dementia by local health board 2019-20

Local Health Board	Number diagnosed (QAIF)	Males: with dementia (CFAS II)	Female: with dementia (CFAS II)	Persons: with dementia (CFAS II)	Number undiagnosed (CFAS II - QAIF)	% diagnosed (QAIF/CFAS II)
Wales	22,005	15,360	26,097	41,457	19,451	53.1%
Swansea Bay University Health Board	2,798	1,773	3,201	4,974	2,175	56.3%
Powys Teaching Health Board	981	875	1,439	2,314	1,333	42.4%
Hywel Dda University Health Board	2,859	2,309	3,733	6,043	3,184	47.3%
Cwm Taf Morgannwg University Health Board	2,733	1,979	3,284	5,263	2,530	51.9%
Cardiff and Vale University Health Board	3,269	1,787	3,409	5,195	1,927	62.9%
Betsi Cadwaladr University Health Board	5,268	3,883	6,429	10,312	5,044	51.1%
Aneurin Bevan University Health Board	4,097	2,754	4,602	7,356	3,259	55.7%

Source: Quality Assurance and Improvement Framework (QAIF), CFAS II study preferences, 2019 ONS mid-year population estimates

The All Wales Dementia Pathway of Standards (2021) aims to ensure when a person is diagnosed with dementia, wherever they live in Wales, they receive a range of interventions, care and support which will enable them to maximise their skills, abilities and quality of life. This communication focuses on **Standard 3** but also connects and aligns with all 20 standards.

Chapter 1 of the bite size communication series provides information and resources that support the importance of utilising dementia READ codes to identify the population diagnosed with dementia within the Welsh regions.

Chapter 2 supports the need to improve the awareness about dementia, to enable and support the public and workforce to recognise and take the steps to seek advice and support about dementia.

Assurance... and Improvement"

The Dementia Action Plan (2018) identifies the need to improve raising awareness about dementia with the ambition for Wales to become a dementia friendly nation. Working to achieve this vision is a requirement, being clear on how, where and why it is important to access assessment and receive a timely diagnosis. In achieving this it will enable people across Wales to receive the care and support outlined in the Wales Dementia Pathway of standards.

The most common early signs of dementia are memory loss and a reduction in practical abilities which lead to withdrawal from work or social activities.

Knowing where to start, where to get help and support about dementia was a key theme identified within the consultation to define the all Wales Dementia Care Pathway of Standards 2021. The need for clear communication and the role of the General Practitioner in this pathway is critical to access the right care and support.

Effective dementia care requires integrated health and social services, enabling people living with dementia and their carers to access assessment, dementia care and support. Dementia is a complex condition and thus will require coordinated responses from across the clinical pathways for General Practitioners, Nurses, Allied Healthcare Professionals, Health Care Scientists, Social Workers and other professional groups, organisations, and others to provide care and support throughout the different stages of dementia.

Raising an awareness of the early signs of dementia, the importance of diagnosis and to access assessment across the workforce will aid improving access to better care and support (Welsh Government, 2018-2022).

Complimentarily to existing dementia awareness campaigns, strategies and resources, from Alzheimer's Society Cymru Dementia Friends, Dementia Friendly Communities and Alzheimer's Disease International, have been developed to assist regions in promoting key messages to both the public and the workforce about the importance of diagnosis and raising dementia awareness.

Chapter 2 aims to:

- Support conversation and assist relationships and partnership working across communities and services within the regions about the importance of a dementia diagnosis and care.

Increase understanding and awareness across the public about the symptoms of dementia and where to get help if they are concerned about cognitive difficulties.

- Increase understanding within the workforce about the importance and benefits of receiving a timely dementia diagnosis.
- Support improving dementia awareness and understanding across the workforce and public.
- Aid better identification of people who maybe struggling with a cognitive impairment to enable them to take the steps to access care and support that might be needed.
- Enable regions to identify this population group and thus support better health and care outcomes for people living with dementia and their supporters.

2.3 Implementation and Evaluation

"Why Implement... this Activity?"

Using the bite size resources will enable regions to focus on targeted improvement work so they can support effective implementation, spread and scale whilst measuring the impact.

Regions should currently be reviewing their referral rates to Memory Assessment Services along with dementia diagnostic rates. Where data shows concerns, regions should be implementing improvement activity to support improvement in identified areas.

Additional bite size activities will be added to this resource as the need is identified by the MAS steering group. Resources and activities are complementary to pre-existing initiatives, for example, Alzheimer's Society Cymru, Dementia Friends and Dementia Friendly Communities.

2.4 Other resources from partners

Regions may also want to consider using other types of posters and resources to advertise any local support other organisations provide e.g. Alzheimer's Society, Dementia Powys Matters and National Dementia Helpline.

Alzheimer's Society Cymru where you find information about becoming a dementia friend, dementia friendly organisation and community.

Improvement Cymru: resources listed below can be found on the Improvement Cymru website's dementia pages.

If you have additional resources to share with others, please email them to PHW.ImprovementCymruDementia@wales.nhs.uk.

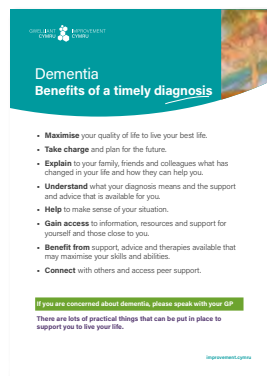
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Chapter 2: Bite Size Communication Resources

What is contained in this communication

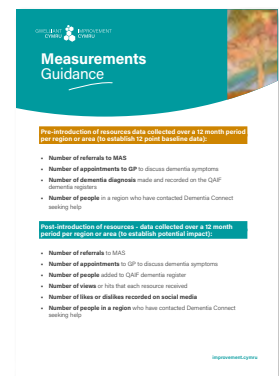
Benefits of a timely diagnosis

Jpegs / Posters / leaflet to be displayed in the GP Surgeries, supermarkets, public transport, community venues, TV & Radio advertising, back of the toilet door, sports centres, libraries, sports venues, pubs and restaurants, pharmacies, places where people may wait, community areas and linked with dementia friendly communities' work. Illustrated are the reasons for the importance of a timely diagnosis.



Measurement Guidance

Suggested data items to collect to establish the impact of the resources.



Dementia: Why diagnose?

Jpeg screensaver / Poster / Newsletter/ clip for internal HB social media for the workforce. Illustrated to support understanding about the importance of referring people for an assessment to the GP when cognitive function and behavioural changes are noted.



Who should be using these resources?

Benefits of a timely diagnosis – This is a public facing resource and should be used by the region to promote across the communities.

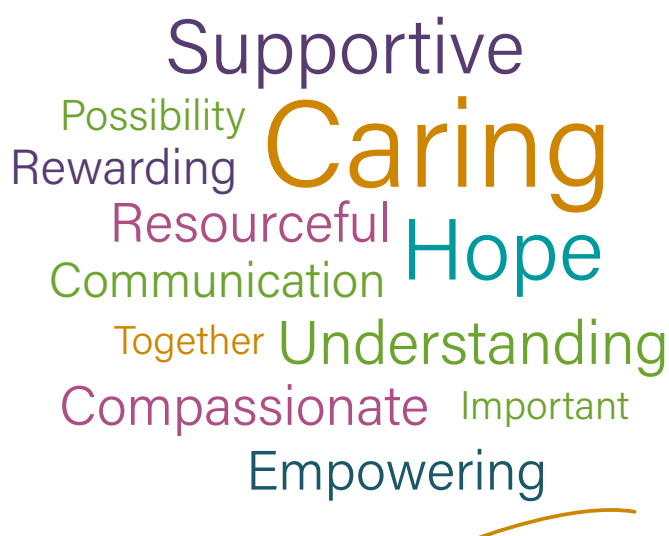
Dementia: Why diagnose? – This is a workforce facing resource and should be used by regions health and social care sectors including community, resource teams, primary care, secondary and specialist clinics, inpatients and social services areas. Resources should be targeted at the workforce across the system, in all areas where clinicians may have contact with people who may be struggling with cognitive impairment and not necessary diagnosed with a dementia.

Measurement Guidance – Workstream leads, regional communication teams and partners to establish the impact of the resources.

Why should you be using these resources?

- **Increase understanding and awareness across the public** about the symptoms of dementia and where to get help if they are concerned about cognitive difficulties.
- **Increase understanding within the workforce** about the importance and benefits of receiving a dementia diagnosis.
- **Increase understanding and awareness** about the benefits of a timely diagnosis.
- **Support improving dementia awareness** and understanding across the workforce and public.
- **Aid better identification of people** who maybe struggling with a cognitive impairment to enable to take the steps to access care and support that might needed.

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Appendix 1

Dementia: Why diagnose? So what?



Dementia

Why diagnose? So what?

Understanding the local population needs will inform service planning to support better health and social care outcomes for people living with dementia and their supports.

No matter the stage of dementia it is important to ensure people can access an assessment to support a diagnosis, if wanted. When and if needed this will provide time and support for the person, family, supporter or carers to:

- **Make sense of the situation**
- **Benefit from available pharmacological and importantly non[1] pharmacological interventions that improve and maximise cognitive skills and abilities**
- **Support better quality of life**
- **Enable access to risk reduction advice and interventions**
- **Gain access to information, resources and support by the right skilled service**
- **Enable connections with others in a similar position to find out what works for them**
- **Gain access to benefits, social support and networks**
- **Consider advance directives, planning for the future, review their financial situation and make decisions about legal affairs**
- **Enable employees to make reasonable adjustments if working**

Appendix 2

Dementia? Benefits of a timely diagnosis



Dementia

Benefits of a timely diagnosis

- **Maximise** your quality of life to live your best life.
- **Take charge** and plan for the future.
- **Explain** to your family, friends and colleagues what has changed in your life and how they can help you.
- **Understand** what your diagnosis means and the support and advice that is available for you.
- **Help** to make sense of your situation.
- **Gain access** to information, resources and support for yourself and those close to you.
- **Benefit from** support, advice and therapies available that may maximise your skills and abilities.
- **Connect** with others and access peer support.

If you are concerned about dementia, please speak with your GP

There are lots of practical things that can be put in place to support you to live your life.

Appendix 3

Measurement Guidance

Measurements Guidance



Pre-introduction of resources data collected over a 12 month period per region or area (to establish 12 point baseline data):

- **Number of referrals to MAS**
- **Number of appointments to GP** to discuss dementia symptoms
- **Number of dementia diagnosis** made and recorded on the QAIF dementia registers
- **Number of people** in a region who have contacted Dementia Connect seeking help

Post-introduction of resources - data collected over a 12 month period per region or area (to establish potential impact):

- **Number of referrals** to MAS
- **Number of appointments** to GP to discuss dementia symptoms
- **Number of people** added to QAIF dementia register
- **Number of views** or hits that each resource received
- **Number of likes or dislikes recorded on social media**
- **Number of people in a region** who have contacted Dementia Connect seeking help

