Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy’n aros am ddiagnosis neu driniaeth

This response was submitted to the Health and Social Care Committee consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

WT 29
Ymateb gan: | Response from: Alzheimer's Society Cymru

Alzheimer's Society Cymru
Unedig Yn Erbyn Dementia
United Against Dementia

Russell George MS
Chair, Health, Social Care and Sport Committee
Welsh Parliament,
Cardiff Bay,
Cardiff
CF99 1SN

Alzheimer's Society Cymru
Alzheimer's Society Cymru
Rhan llawr 1 af/Part 1st Floor
Adeilad S4C/S4C Building
Parc Ty Glas
Llanishen
Caerdydd/Cardiff
CF14 5DU
Website
alzheimers.org.uk

13 January 2022

Dear Chair,

I am writing to respond to your invitation to give evidence to the Health, Social Care and Sport's Committee Inquiry into waiting times in Wales. Alzheimer's Society Cymru firmly believes that this is a vital piece of work that, if managed correctly, can have an incredibly positive impact on the care received by people living with dementia.

Although there is no concrete data on the increase in numbers on Memory Assessment Service waiting lists across Wales, Alzheimer's Society Cymru has heard anecdotal evidence that, in the run up to Christmas 2021, there were round 4000 people waiting for a Memory Assessment Service appointment in Wales. Unfortunately, we do not know how many people currently accessing Memory Assessment Services were in the process of receiving a diagnosis of dementia in Wales when the Covid-19 pandemic began, and are therefore unable to place a realistic estimate on the waiting list numbers in Wales.

With Wales diagnosis rate for dementia dropping to around 50% in the midst of pandemic, it is clear from the anecdotal evidence mentioned above that Wales is likely to add around 2000 people to the estimated number of 50,000 people living with a diagnosis in Wales currently.

As the Committee understands, Dementia is a profoundly life-changing condition, and an early diagnosis opens the door to future care and treatment. It helps people to plan ahead while they are still able to make important decisions on their care and support needs and on financial and legal matters. It also helps them and their families to receive practical information, advice and guidance as they face new challenges.

Therefore, the earlier in their dementia journey a person receives their diagnosis, the easier it can be to plan future care, such as powers of attorney, advanced care plans, and wills that can have a profound impact on the quality of care received by a person living with dementia, and lessen the impact on an unpaid carer and statutory services.

We have already seen statements from both Betsi Cadwaladr and Cardiff & Vale Health Boards, alongside their respective Local Authorities and service providers, asking those delivering unpaid care in Wales to do more to ease the burden on hospital services, something that has caused

Mae'r Gymdeithas Alzheimer yn elusen gofrestredig yng Nghymru a Lloegr (296645) ac ar Ynys Manaw (1128)
Cwmni cyfyngedig gan warant, cofrestrwyd yng Nghymru a Lloegr (2115499) ac ar Ynys Manaw (5730F)
Swyddfa gofrestredig: 43-44 Crutched Friars, London EC3N 2AE.

Alzheimer's Society is a registered charity in England and Wales (296645) and the Isle of Man (1128)
A company limited by guarantee, registered in England and Wales (2115499) and the Isle of Man (5730F)
Registered office: 43-44 Crutched Friars, London EC3N 2AE.

undue stress, concern and will have lasting impacts on the physical and mental health of those delivering care and those receiving care in Wales. Alzheimer’s Society Cymru is concerned that the delay in receiving a diagnosis of dementia, meaning that the person will likely be diagnosed later in their journey, will only increase the burden on our already over stretched unpaid carers and statutory services.

A later point of diagnosis along a dementia journey means that the person will be engaging with statutory services later, likely with more complex needs, and likely with more complex needs for their carer too.

We are also concerned that increased waiting lists will deter those who are worried about their memory from seeking help and support from Memory Assessment Services as to ‘not increase the burden’ on their loved ones or statutory services by receiving a formal diagnosis. We are concerned that this will lead to a further misrepresentation of the number of people living with dementia in Wales, and will lead issues with attempts to increase the efficacy of statistics on dementia and caring for people living with dementia in Wales.

Alzheimer’s Society Cymru therefore calls on the Committee to consider four recommendations as part of this inquiry:

- Increase support to statutory services to provide person centred care, tailored to meet individual needs, of people living with and affected by dementia.
- Increase support to statutory services to facilitate increased staff recruitment, retention and training to provide person centred care to people being diagnosed later in their dementia journey.
- Provide funding to increase awareness of the importance of an early diagnosis and the need for advanced care planning as part of this process.
- Develop monitoring and data collection criteria so that the impact of waiting lists, and the pandemic in general, on people living with and affected by dementia can be measured to allow for a stronger evidence base for policy decisions in the future.

As the Committee can see from the evidence above, we do not know the true impact of the Covid-19 pandemic on people living with and affected by dementia, nor on the services that diagnose and provide statutory care. However, we strongly believe that by implementing the four recommendations above, we can somewhat mitigate the impact of Covid-19, and future-proof services, using evidence based policy, to allow Wales to cope should we ever find ourselves in a similar situation in the future.

Kind regards,

Sue Phelps