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This response was submitted to the [Health and Social Care](#)  
[Committee](#) consultation on [mental health inequalities](#)

MHI 85

Ymateb gan: | Response from: Age Cymru

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**Senedd Health and Social Care Committee -  
Mental Health Inequalities consultation response February 2022.**

Age Cymru welcomes the Senedd's inquiry into mental health inequalities. This is an increasingly important area of work as mental health issues for older people have been exacerbated by the coronavirus pandemic.

In preparing this consultation response we have considered a range of research, information on service and other support availability, and feedback from older people and older carers on access to health and social care. This response also focusses on the multiple disadvantage that a variety of older people in Wales face with mental health support. We assume that the wider underlying causes of mental health inequalities are already understood by the Health and Social Care Committee regarding poverty levels and protected characteristics other than age, and how these additional intersecting factors affect people across Wales in a number of ways.

These additional factors can impact older people disproportionately through incremental negative life experiences that have happened through discrimination: over time, distrust can develop, and so older people may be less likely to approach services for help until they reach a point where support is vital for them to continue to live independently.

Later life brings distinct challenges that can test resilience and contribute to the onset of distress or mental health problems or may trigger recurrence of existing or previous problems. These are events and transitions that can happen at any age but are more common from age 50 onwards and can be disruptive.<sup>i</sup>

Dementia is a condition predominantly associated with older people and this where the majority of mental health services for older people have been concentrated. We are concerned that there are gaps in services as well as gaps in knowledge across Wales on wider mental health needs of older people.

We believe that one of the consequences of the pervasive ageism in society<sup>ii</sup> results in older people not having access to mental health support that they would benefit from. Mental health conditions in older people are not an inevitable part of ageing; there are positive things people can do at any age to look after their mental health and if an older person does develop a mental health condition, recovery is possible for many conditions with the right support. With mental health being increasingly (and rightly) seen as a priority for improvement and investment, it is essential that older people's mental health needs are not left behind.

## **1. Which groups of people are disproportionately affected by poor mental health in Wales? What factors contribute to worse mental health within these groups?**

Older people are as likely to experience mental health difficulties as other age groups, yet their needs are often overlooked. Prior to the pandemic statistics showed that the most common mental health condition in older people was depression, affecting 22% of men and 28% of women aged 65 or over. This rises to 30% for those that are unpaid carers. These statistics will have increase with the effects of the pandemic. Older people going through a bereavement are up to four times more likely to experience depression than older people who haven't been bereaved.<sup>iii</sup> Depression in later life is the major risk factor for suicide and 80% of people over the age of 74 who die by suicide have a history of depression.<sup>iv</sup>

1 in 14 people live with dementia, which rises to 1 in 6 for those over the age of 80.<sup>v</sup> Dementia is not itself mental illness, but the mental health effects of this progressive brain disorder mean it falls under the area of mental health treatment. Wales has the second highest prevalence of dementia in the UK<sup>vi</sup> and in 2019, 46,000 people were living with dementia in Wales.<sup>vii</sup>

Surveys and feedback from older people during the pandemic have demonstrated increased levels of depression and anxiety; partly through a lack of access to services and partly due to the effects of lockdowns. Many older people have experienced poorer physical health, increased levels of social isolation, increased levels of loneliness, bereavement, and a lack of social and therapeutic opportunities that can help maintain and improve mental health. In our second survey of older people's experience of lockdown we asked respondents what their largest challenge was as Wales moved out of lockdown. The second most frequent response (after fears of crowds) related to confidence and anxiety levels,<sup>viii</sup> which demonstrates the increased issue for some older people. Our survey showed that loneliness was much more of a challenge for those aged over 80 during the lockdown (55% compared with 37% of respondents). This is an increased risk factor for depression.

Older carers have been under incredible pressure during the pandemic due to a lack of usual care and support from health and social care, as well as witnessing those they care for deteriorating. This undoubtedly affects their mental health. Our Age Cymru and Carers Trust Wales report, *For the Moment*<sup>ix</sup> on older carers' experiences during lockdown showed that 60% were feeling stressed and 63% were more tired. The survey found that 12% had given up paid employment to be a carer. The loss of employment is a risk factor for reduced mental wellbeing in any age group, and for older people who are less likely to be able to return to paid employment this increases the risk.

A larger UK-wide report from Carers UK also found that older carers are at higher risk of mental health issues. Their survey found that 81% of carers had taken on increased hours of care, often with reduced or zero outside support. This has had a significant and detrimental impact on carers' health and wellbeing, with over two thirds of carers reporting that their mental health has worsened as a result of the pandemic.<sup>x</sup> Age Cymru welcomes the additional resourcing that has been allocated

recently by Welsh Government that will over time help overcome these issues. But carers were struggling before the pandemic, so it is important that such funding continues and that further development work is undertaken to understand and address the full range of their needs.

Some older carers are living with multiple disadvantage. Our survey of older people's experiences of the most recent lockdown<sup>xi</sup> showed 23% of all respondents had taken on additional caring responsibilities or started looking after someone during the previous year. More detailed data not fully seen in our final report shows this rises to 43% for older people from Black, Asian and Minority Ethnic communities. As such, people from these communities will have an increased need for mental health support.

Older LGBTQ+ people are less likely to have access to support from biological family as a result of discrimination within families. Older LGBTQ+ people are less likely to access health and social care because of a fear of discrimination and so it is likely that their mental health has been more affected through the pandemic also and will have a higher need for mental health support.

Of grave concern are the adverse effects of lockdown on older people living in care homes' mental health. The Alzheimer's Society estimate that 80% of care home residents are living with dementia and less than half of residents are offered opportunities for activities. Prior to the pandemic 40% of older people living in care homes had depression<sup>xii</sup> and undoubtedly this will have increased as a result of the pandemic. Over the last two years we have seen a disproportionate number of deaths in care home settings, and this in itself increases the impact of bereavement on residents in the same homes and contributes to poorer mental health.

Care home visiting was stopped under lockdowns and residents were forced to stay in their rooms for weeks at a time in cases where Covid 19 was present to reduce the risk of transmission. The condition of many people living with dementia has rapidly deteriorated. The full picture is still emerging of the impacts the pandemic has had on care home residents. Age Cymru's *Tell Me More* project has sought to capture the experiences of care home residents in their own words and voices.<sup>xiii</sup> The resulting video from this is best listened to for the impact the pandemic has had to be really heard. We hear one lady say,

*"I could see a lot of differences in people's minds - the Alzheimer people – what I think it is, is they miss their family, probably more than we do [...] If people were truthful, you would admit you get despondent. It's gone on too long."*

It is vital that care home residents are given additional care and support to recover from the pandemic. The current crisis in care worker retention and recruitment has put additional pressure on care homes who are struggling to deliver the basics of safe care. This also comes at a time when a stable, skilled workforce has never been needed more. Feedback from older people's groups across Wales says they feel they have been left behind whilst other people are able to get on with life.

Age Cymru's cARTrefu project has delivered creative residencies and workshops (e.g., art, photography, music, spoken and written word), to care home residents from professional artists across Wales between 2015 and 2022. It is believed to be the largest project of its kind across Europe. In the first phase, 65% of participants had a diagnosis of dementia. People who have reduced ability to communicate such as those with dementia struggle with self-expression, and this can have a severe effect on their mental health and can speed up deterioration.

An independent evaluation of that phase of cARTrefu found that the programme had a significant positive impact on older people's well-being, especially those living with dementia. It also saw signs of residents regaining skills that had disappeared. Creative activities provide both social and physical activities that allow self-expression and increased communication. Recurring themes of improvement from the evaluation included an increase in self-confidence, morale, cognitive stimulation and development of new relationships and friendships with other residents and staff. The evaluation showed that cARTrefu project delivers a social return of £6.48 for every pound spent.<sup>xiv</sup>

## **2. For the groups identified, what are the barriers to accessing mental health services?**

We are concerned that there is an ageist culture that affects older people's access to treatment, care and support. A survey carried out by the Older People's Commissioner in 2019 found that almost 1 in 10 older people have been made to feel too old to receive health services<sup>xv</sup> and international research and evidence highlights how health care services can ignore the specific needs of older people affected by mental health conditions through a 'one size fits all' approach that ignores differences in presentation and effects on older people.<sup>xvi</sup>

Research and data analysis indicate that, despite significant prevalence of depression among people aged 65 and over, they are less likely to recognise symptoms of common mental health problems, and those that do are less likely to seek help from family, friends or a healthcare professional.<sup>xvii</sup> As with other age groups, older people often do not recognise themselves as experiencing mental health issues - putting it down to 'feeling low,' and so are unlikely to approach services for help. An additional focus is needed for older people in recognising that support is available and that there should be no stigma in coming forward for help.

Research commissioned by the Older People's Commissioner found that 17% of said they had needed mental health support in the last twelve months, but only 12% had sought it.<sup>xviii</sup> UK wide, 1 in 4 older people in the UK live with a common mental health condition but only 15% of these are receiving help from the NHS.<sup>xix</sup> For older carers, 51% of respondents said that they had not tried to access support either because they don't know what's available, are reluctant to seek external help for either themselves or the person they care for, or don't have the time.<sup>xx</sup>

If people are unable to access care at the time they need it, their situation can escalate and require more acute interventions. Our *Experiences of people aged 50 or over in Wales during the Covid-19 lockdown, and the road to recovery* survey report<sup>xxi</sup> highlighted issues with access to health and social care generally. GP services are usually a person's first port of call for physical and mental health issues and were the most frequent focus of more detailed responses. 40.5% of respondents had issues with accessing GP services and 6% responded that they could not access GP services at all. Though the situation with access is changing as we move out of lockdown, we are concerned that many people have not yet approached services for help.

For those that do recognise that they need help, finding the right help can be difficult. For those that are digitally literate and have access to the internet, it can still be difficult to see what help is available. At Age Cymru we have recently undertaken a rapid desktop research on access to information and support for older people's mental health needs. We have looked at information available on Welsh Health Board websites; regional population needs assessments in relation to older people and mental health (which are due to be revisited shortly); and used the Dewis portal to look at what programmes, services, therapeutic activities and social groups are available in different parts of Wales. We have concluded that information is often unclear, information can be fragmented, and some regions (predominantly more rural) are lacking in either information or support, or both:

- Population needs assessments (PNAs) vary across Wales in terms of the level of detail and understanding of the needs of older people with mental health issues. Little consideration is given to the specific mental health needs in later life. Whilst there are some assessments that seem to have considered older people's needs holistically, the majority do not. Little information is included in PNAs that actually highlight gaps in services for older people with service information mainly focussing on dementia.
- Each Health Board has information on their website that details what services they have in place for people with mental health issues, but many fail to include services specifically for older people. Where these are included, it is unclear what form of help is available.
- The main focus of provision for older people's mental health on Health Board websites is around dementia and rarely covers other conditions.
- Health Board sites appear to not have been updated sometimes and can contain out of date information and links to programmes/services that no longer appear to exist, which can act as a barrier to older people seeking help.
- The language used on Health Board sites can act as a barrier to understanding of mental health conditions and what is available.
- The Dewis portal is an online-only tool that can be unwieldy for older people (and others) to be able to navigate to information relevant to them, and not all are digitally enabled.

- The Dewis portal details many areas of support and signposting that rely on short term funding. This means that services will be struggling with sustainability once funding runs out.

A national, regional and local focus is needed on recognising signs of mental ill health, knowing where to go to get help, what services and support are available and how to access them (both on and offline).

In (1) above we drew attention to the expected poorer mental health of older carers and how older people are not offered the same support as younger people with their mental health. In the *For the Moment* report, 51% of carers that responded said they had not tried to access support either because they don't know what is available, are reluctant to seek out external help, or they don't have the time.<sup>xxii</sup> This is also likely to be true when trying to get help with mental health.

The older LGBT community have lived through times when coming out may result in a range of serious negative repercussions, including criminalization, through prejudice and intolerance. Though attitudes have changed, tolerance and understanding are still not universal and so our LGBT community have valid concerns regarding how they are treated. This is also a group of people that are more likely to experience mental ill health because of the discrimination they have faced. One study found that 26% of LGBT people had experienced discrimination related to their gender identity or sexual orientation from health and social care professionals.<sup>xxiii</sup> As such this acts as a barrier to those that need it seeking help for their mental health.

### **3. How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?**

We are concerned that there are gaps in services, as well as gaps in knowledge across Wales on the specific mental health needs of older people. The majority of mental health services for older people are for people living with dementia. There is a growing need for these services, given the increased numbers living with this illness. However, dementia is far from the only mental health condition that affects older people and there is a need for an increased focus on improving support in this area.

We are concerned that unconscious ageism mean that older people do not get access to talking therapies and may be being over prescribed medication when other therapies would be more beneficial. In the years prior to the pandemic there had already been a large increase in the number of older people prescribed with anti-depressants.<sup>xxiv</sup> Through the lack of face-to-face appointments and associated services to refer to, it is likely that this will have increased. Though anti-depressants can be beneficial in the short term to help with recovery, medication alone does not help people address the underlying causes and as a result people remain on medication with its associated side effects much longer than should happen. As such it is important that medical reviews and health checks resume at pace and that patients' medication levels are reviewed. An examination needs to be undertaken on

increased prescribing levels through the pandemic and a focus on the availability of therapies that can be more beneficial than ongoing prescribing of anti-depressants.

### Dementia services and wider support

Prior to the pandemic there were differences across Wales in levels and speed of dementia diagnosis and access to help. Services and support for people living with dementia and their carers have been severely disrupted through the pandemic: memory clinics have been closed, diagnoses have been via zoom calls (where this is at least a partially viable option), and care packages have reduced or disappeared. There have been increasing delays in diagnosis, which for carers also means a lack of access to support as social care assessment and allocation seems to rely on a diagnosis before care packages can be arranged.

For those that already have a diagnosis, memory cafés, day centres and other social opportunities have been closed, and this is against a backdrop of a funding squeeze that had already reduced the availability of universal social opportunities. Loss of socialisation and meaningful activity affects everyone, but specifically for people living with dementia (who often pre-pandemic had limited social contact), the effects have been particularly devastating.

People can already be living with other health conditions and their partners and family can also be living with illness, so with co-occurring needs, it is vital that services are provided seamlessly.

People living with dementia are more likely to be admitted to hospital and it is estimated that 1 in 4 admissions are those living with dementia. The current crisis in delayed transfer of care will have disproportionately impacted this group of people and with restrictions on visiting, they have been severely impacted by loss of social contact at an already incredibly stressful and confusing time. This can contribute to a decline in functioning and a reduced ability to return home to independent living.

Improving the experience of the large number of people with dementia in hospitals is key to improving the NHS overall. If people with dementia were supported to leave hospital one week earlier than they currently do, significant savings might be achievable across the system as a whole. Much of the money currently spent on treating people with dementia in hospitals could be more effectively invested in appropriate community services outside hospitals, as well as workforce capacity and development.

Because of the specific needs of people living with memory loss it is vital that continuity of care is provided by known and trusted staff. Care at home allows older people living with mental ill health to continue to live independently in a community they know and have been happy in. Delays in care packages are causing considerable distress for people living with dementia and their carers and in some cases have meant that older people living with dementia have had to move to residential care sooner than they wish to and long before they needed to.

In one instance in recent months, our information and advice service was approached by a unpaid carer for a person living with dementia whose partner also



has significant and serious health issues. They had been assessed as needing a considerable package of domiciliary care and had already been waiting 6 months for this to be arranged. They were offered some interim care whilst waiting for the full package of care to be available from what seemed to be a range of care agencies who could not guarantee specific call times. They had to refuse this as they felt the disruption caused by different carers coming in as a less planned package would be too much for the person living with dementia to cope with, despite the additional stress the lack of care would place on unpaid carers/close family and the person with significant health needs.

One area of support that people living with dementia and their carers greatly value is the care provided by specialist Admiral Nurses. Increasing the availability of support through them would be beneficial.

#### **4. To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?**

Guidance and information related to mental health provision often does not include any reference to the different specific needs of older people. For example, the Mental Health Code of Practice makes few specific references to older people, with the majority of those relating to safe handling and the need for staff to be trained in older people's needs. Without reference to the differences in presentation and needs, it is difficult to see how services are able to provide the right support at the right time.

A key concern is the translation of policy into practice. The development of the Dementia Standards Pathway is a positive step and a good example of how multi-disciplinary work has identified strengths and weaknesses of the system and identifies where improvements can be made. It is vitally important that the current work is closely overseen to ensure that pathways are in place for diagnosis, care and support for people living with dementia. In the longer term it is also vital that consideration is given on how services can meet the holistic needs of the increasing number of people living with dementia.

Public services' targets still seem to be output rather than outcome based. The pandemic has necessitated a reduced level of data collection and in some cases scrutiny of service delivery and multi-agency groups responsible for development have been unable to meet. Data collection needs to be resumed urgently so that the scale of the issue can be addressed. We were pleased to see that the national memory assessment sub-group will shortly be resuming meetings. Whilst such work has been on hold, it is impossible to see the full picture of length of delays in assessment and access to treatment.

#### **5. What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?**

Targeted action is needed to ensure that information and advice, referral mechanisms, care pathways, services and wider support consider the specific needs of older people to maintain and improve their mental health are available to those that need it.

The needs of older adults are best met in specialised mental health services, which understand the complexity of older people's needs and have the expertise to meet them.<sup>xxv</sup> As such, an examination is needed of the range and availability of mental health support for older people.

The pandemic has impacted the mental health of older people in care settings disproportionately. It is important that early steps are taken to address this impact. It is vital that care home residents have access to an ongoing suite of medical, physical, social and therapeutic activities that can reduce deterioration in physical and mental health.

As older carers struggle with time and energy to address their own physical and mental health needs, additional targeting to understand their needs and how they can be met is needed. Specifically for those caring for someone living with dementia, feedback from our services and partners has highlighted very poor (and sometimes non-existent) communication from mental health professionals to help them understand the condition and how best to support their loved one(s). They feel that they are 'going it alone,' particularly at this time with a lack of home care services. As discussed earlier, those living with dementia and their carers are more likely to have co-occurring conditions that make it difficult for them to access the range of care and support that they need. An examination of the needs of carers in terms of what information and advice they need, and what services can do to support them is needed. Such work should involve older carers at every stage.

We have seen a marked deterioration in people living with dementia through the pandemic so it is vital that memory clinics, memory cafes and other social opportunities are more rapidly opened up than at present to prevent further deterioration.

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<sup>i</sup> British Association for Counselling and Psychotherapy, October 2020 <https://www.bacp.co.uk/about-us/advancing-the-profession/influencing-decision-makers/older-people/counselling-older-people/>

<sup>ii</sup> 2021 Centre for Ageing Better, Reframing Ageing: Public perceptions of ageing, older people and demographic change. <https://ageing-better.org.uk/publications/reframing-ageing-public-perceptions-ageing-older-age-and-demographic-change>

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- xx <https://www.ageuk.org.uk/cymru/our-work/carers/for-the-moment---summary-of-findings--from-older-carers/>
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- xxii <https://www.ageuk.org.uk/globalassets/age-cymru/documents/carers-project/age-cymru-carers-report---english.pdf>
- xxiii The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people [the\\_last\\_outing.pdf](the_last_outing.pdf) ([lgbtsand.com](https://lgbtsand.com))

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<sup>xxiv</sup> <https://www.cam.ac.uk/research/news/antidepressant-use-more-than-doubles-among-over-65s-in-two-decades>

<sup>xxv</sup> <https://www.england.nhs.uk/blog/mh-better-access/>