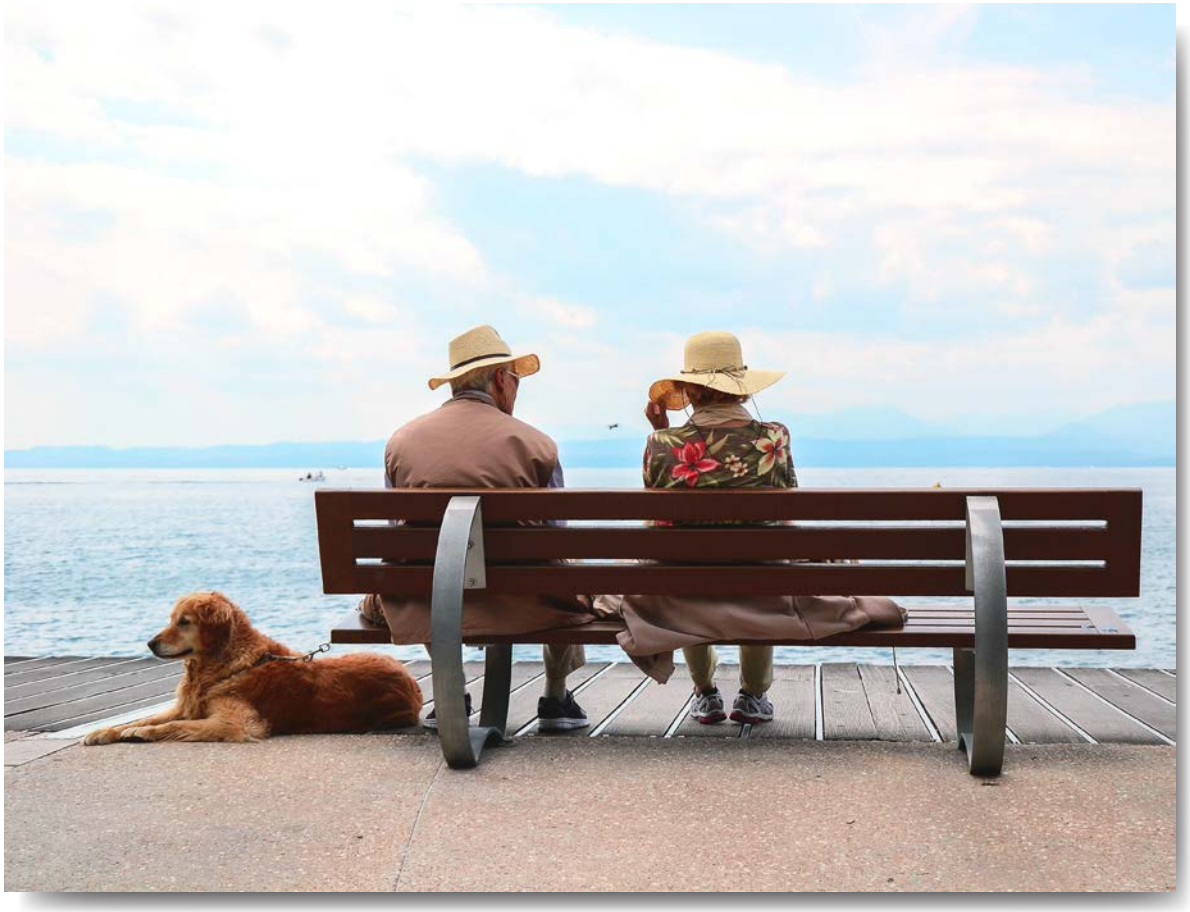
LIVING WELL IN LATER LIFE

THE CASE FOR CHANGE



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Foreword

Positive mental health is for everyone. Our goals, occupations, employment status and lifestyles may be very different but we all want the opportunity to live well, in our community, on our own terms.

In 2014 the NSW Government accepted *Living Well: A Strategic Plan in Mental Health in NSW 2014-2024*, developed by the Commission to articulate this vision and embed it across the work of all Government agencies and more broadly.

Living Well presents an inclusive, whole-of-government, whole-of-community and whole-of-life perspective. The approaches it advocates – local service planning, an emphasis on wellbeing and early intervention, support for recovery, and trauma-informed service delivery – are valuable at all stages of life for people from all cultural backgrounds.

This is the backdrop against which the Commission has developed the two resources that form *Living Well in Later Life: The Case for Change* and *Living Well in Later Life: A Statement of Principles*.

In our community the mental health and other needs of older people are often addressed separately from those of younger people. There are different age-based services, alternative funding mechanisms and a set of assumptions about older people that influence their wellbeing and the support they receive when they experience mental health challenges.

For these reasons it is important to say explicitly how the framework of *Living Well* plays out in the lives of older people. We have done this in *The Case for Change*, which maps the experiences of older people against the domains of *Living Well*.

This work has highlighted a number of opportunities, which require us to challenge prejudices about older people that are deeply embedded in our systems. We must support people to seek help earlier when they experience distress, which is categorically not an inevitable part of ageing. And we must accept that recovery – including the hope that things will get better – is essential later in life as it is at any age.

Above all we need to respect older people and include them, in our communities and in decisions both about their own lives and about how we can do better in providing appropriate services.

These issues are summarised in *A Statement of Principles*, which sets out the fundamental challenges that governments, service providers and the community as a whole must address if we are to support people to live well in later life.

Living Well in Later Life has been energetically supported by an expert group including representatives from the Council on the Ageing NSW, the Faculty of Society of Old Age (NSW Branch) of the Royal Australian and New Zealand College of Psychiatrists and the NSW Health Education and Training Institute. The group has provided invaluable advice including detailed comments on drafts and I am grateful for their commitment.

Many other organisations - listed on page 39 - have made submissions and joined targeted consultations, and their generous sharing of insights is greatly appreciated.

In particular I thank the older people who met with the Commission. Their views and voices are at the heart of these resources, along with those of their families and carers. Their experiences – as community members, Elders, users of services and peer workers – are an inspiration to all of us.

John Feneley
NSW Mental Health Commissioner

Contents

INTRODUCTION

The Mental Health Commission of NSW is an independent statutory agency responsible for monitoring, reviewing and improving mental health and wellbeing for people in NSW.

Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024[1], developed by the Commission and adopted by the NSW Government in December 2014, maps a demanding agenda for change that puts people, not processes, at the heart of its thinking in the care and support of people who experience mental illness.

This paper investigates how the *Living Well* agenda can best be applied in the lives of older people, across the whole spectrum of government and community-managed services. It considers the best approaches to supporting positive mental health and wellbeing for all older people, as well as how to ensure appropriate, recovery-focused supports are available to older people who have specific mental health needs, so they can live well in later life. These considerations are timely for our community, as the 10 year implementation period of *Living Well* is set to coincide with significant growth in the number and proportion of people aged 65 years or older[2].

Older age, wellbeing and mental illness

Getting older, like all stages in life, should be a time of contribution and fulfilment. To achieve this, people need access to mental health services and social supports in their community. Yet services are often not designed to cater for the unique requirements of older people, or able to recognise the impact of experiences and events which occur in the process of growing older. There may be issues such as social isolation, leaving the workforce, reduced mobility or the death of loved ones.

Ageing can be a liberating time in many ways. There can be more opportunity for personal interests, family, and contributing to the community. However, being an older person with a lived experience of mental illness can also come with its challenges.

Older people report there is a lack of prevention and early intervention programs that resonate with them. The services and programs that are available can be difficult to navigate, and there are also financial burdens in later life that may be exacerbated by not being part of the workforce. Older people say that the loneliness, social isolation and stigma associated with ageing and mental illness can also impact negatively on their mental health and wellbeing.

The intent of this paper is to highlight the specific challenges for older people who experience mental illness, and also indicate the changes required to ensure the good mental health and wellbeing of all people as they age. It is informed throughout by the views of older people with a lived experience of mental illness, as well as the expertise of representatives of the mental health and ageing sectors.

The paper highlights a pressing need to ensure that systems and services are appropriate and effective in meeting the mental health needs of older people. Attitudes are important too. Positive individual and community views of ageing, that promote dignity, support and respect for what older people offer in our society, can go a long way towards helping people to live well in later life.

This paper complements *Living Well* and presents key areas for action aligned with the six principles of *Living Well*.

What we know

- The majority of older people will experience good mental health. However, 9.5 per cent experience mental illness, and almost 11 per cent experience a high level of psychological distress[3].
- Older people are at heightened risk for anxiety and depression, particularly where there is a co-occurring physical illness, dementia, disability, or difficult life experiences such as bereavement, or social isolation[4].
- 52 per cent of aged care residents experience symptoms of depression[5].
- The highest age-specific suicide rate across all ages is observed in males 85 years or older[6].
- There were an estimated 3.68 million people aged 65 years and over living in Australia as of June 2016[7].
- The over-65 population is projected to increase to between 5.7 million and 5.8 million by 2031[8].
- In NSW, 15.9 per cent of residents are aged 65 years and over including 168,430 people aged 85 or more[9].
- The population growth of people aged 65 and over grew by a staggering 18 per cent over the five years between June 2010 and June 2015[10].
- While mental illness is more common in younger people, older people tend to have more chronic forms of mental illness[11].

Local residents of Lakemba

MAKING IT LOCAL

Community is at the heart of positive health and wellbeing for all ages, including older people. Social isolation and negative community attitudes towards ageing are important issues that may impact on the mental health of older people. Service access and the willingness to use services can be barriers to care and support, particularly for older Aboriginal people due to negative life experiences[12]. Together these issues represent opportunities for locally tailored actions to improve attitudes, connectedness and culturally appropriate services for older people within the community.

Localised decision making is the cornerstone of state and Commonwealth government mental health and health policies. Primary Health Networks (PHNs) are a Commonwealth funded mechanism for coordinating and integrating state and Commonwealth funded services into a community of practice, and have the capacity to purchase services in response to identified gaps. Mental health, drug and alcohol and suicide prevention have been identified as some of the key priorities for PHNs, with this presently addressing the life span, rather than specific population groups. Consultation and co-design of services with older mental health consumers and their families and carers are key to the delivery of accessible and responsive local mental health and health services for older people.

Strengthening local action

Older people should be valued for the wisdom and experience they bring to their friends, families, social networks and communities. Local communities have much to gain through developing and implementing health and community support services to assist and work with older people to live well.

Community resilience and wellbeing for older people living with mental health issues requires access to mental health and aged care community based services as needed, access to safe and affordable housing, participation in meaningful activity and availability of social supports.

The role of local community groups in strengthening wellbeing and mental health can be improved through developing more inclusive approaches with older people to reduce the impact of social isolation or to ameliorate the impacts of poor physical health, disability, dementia, disconnection from family and friends, poverty and housing and financial instability. These responses should focus on overall mental health and wellbeing, and minimising social isolation, which is a particular issue for older people, especially those with mental illness[13].

Identifying and understanding the specific needs of the local older population with mental illness is crucial to developing integrated and comprehensive local service responses. The role of local general practices, aged care and community services, community agencies and health care services in providing locally appropriate and accessible responses is key. Local councils and other community based organisations can also assist in developing the capacity of the community to keep older people mentally well through simple measures such as the provision of safe, free public places to meet and socialise, along with community transport or more accessible and frequent public transport. Clear information about the availability of toilet facilities can also reduce anxiety about excursions from home[14].

Web and paper-based information about locally available care and support services for older people and their carers could be improved by involving older people and their carers in the co-design or co-production of the content and format.

Stigma continues towards older people, especially views that associate ageing with decline. Older people who experience mental illness reported during consultation with the Commission that they

sometimes felt further stigmatised by their age, especially if they experienced mobility issues. Stigma or discrimination may make people hesitate to seek services, resulting in them not receiving the care they need or increasing their isolation and mental health issues[15]. Stigma can also impact at the system level, manifesting in policies, practices and cultural norms that restrict the opportunities, resources and wellbeing of older people with a mental illness. It can also manifest as a lack of specialist services, and too few age-friendly community services[16].

Stigma reduction requires communities to build respect for older people, and for services which engage with older people or their carers to be more understanding and inclusive in how they work and the values they espouse. Information about wellbeing, mental health and illness needs to be widely available to individuals and the community in order to dispel myths, address cultural understandings of mental health and increase the expectation of mental wellbeing in older age.

All members of the community, especially older people, can play an important role in driving positive messaging around ageing and promoting positive ageing to their peers and the broader community.

Aboriginal communities

The Commission has been privileged to meet with Aboriginal communities across the state and hear about their experiences, views and ideas for change[17]. Discussions and consultations with key organisations, such as the Aboriginal Health and Medical Research Council of NSW, Aboriginal Affairs NSW and the Healing Foundation, have also contributed to enhanced understanding of Aboriginal experiences and key priorities.

Aboriginal culture places great value on Elders, whose knowledge is valued and respected. Their sharing of knowledge and wisdom in their communities creates a sense of belonging and kinship and is a protective factor for social and emotional wellbeing. Elders facilitate connection to land, culture, spirituality, family, and they may promote self-determination, community governance and cultural continuity. This relationship is mutually beneficial and contributes to the social and emotional wellbeing of Elders.

We also know that Aboriginal people experience poorer mental health compared to non-Aboriginal people as a result of issues that include discrimination and racism, grief and loss, economic and social disadvantage, substance use, physical health problems, geographic isolation and poorer access to health care.

Older Aboriginal people have often been exposed to exploitation, segregation and the impacts of the Stolen Generations and may also be affected by mental health issues in their community in their roles as Elders, family members, community members and leaders[18].

Aboriginal communities should lead the much needed work to identify and deliver services that are culturally sensitive and appropriate for older people, and given the health disparities in their community, responses to ageing should not be dependent upon a person's given age but on how they are ageing.

Aboriginal people have a holistic view of health, which includes physical, cultural, spiritual, emotional and social wellbeing and community capacity and autonomy. Services need to respond holistically if they are to meet the social and emotional wellbeing needs of Aboriginal people. Partnerships between services and Aboriginal communities, Aboriginal Health Workers and Aboriginal Mental Health Workers is key to creating culturally informed services. Engagement and consultation should be undertaken as a priority and be visible to the Aboriginal community, particularly when new services or initiatives are implemented.

CASE STUDY

Tackling the stigma of mental health and ageism

A unique peer worker programme developed on the NSW Central Coast is helping revolutionise the way older clients interact with those supporting their mental health journey.

They count among their ranks a career accountant, a retired engineer and the former CEO of a multi-national charity.

Yet in addition to bringing decades of professional experience to the table, this inspiring group of individuals are also using their own lived experiences of both ageing and mental illness to provide inspiration and support for those who require it most.

The trio are part of a small group of individuals who are either employed or volunteer as part-time peer workers for the Central Coast Older Persons Peer Support (CCOPPS) program.

The program teams peer workers aged 50-plus with mental health workers and consumers and is a joint initiative of the local Specialist Mental Health Services for Older People (SMHSOP) and the community-managed organisation Central Coast Primary Care.

SMHSOP service manager Raichel Green says the programme, believed to be the first of its kind designed specifically to meet the recovery needs of older consumers, arose from the lack of peer workers with a lived experience of ageing and mental illness.

Having consulted extensively with intended users of the service, in late 2015 Ms Green successfully applied for a $50,000 grant to run a 12-month pilot scheme. Every aspect was designed, developed, implemented and evaluated in association with those at the coal face, including consumers and peer workers. The program has now been embedded as a core part of the service offering.

> *"Our consumers told us they wanted someone who knew what it was like to lose a partner at the end of life, to know what it was like to consider going into supported accommodation, to know what it was like to become frail or to have multiple physical or mental health problems. They felt they couldn't have those types of conversations with younger peer workers." (Raichel Green)*

Ms Green says the initiative operates across three broad strategies. The first has older peer workers working one-on-one with consumers to undertake personal recovery and lifestyle management, with a focus on reducing the impact of social isolation.

The second is a four-week group program, co-facilitated by both an older peer worker and a clinician, called Roads to Recovery. The third strategy provides community education about older people's mental health and utilises older peer workers' purposeful storytelling with the aim of challenging the dual stigmas attached to both ageing and mental health.

While the programme has not been without its challenges, it has also been credited with improving the wellbeing of the people receiving the service as well as those who provide it.

CCOPPS peer worker Vicki Schramko describes being involved with the program as "the pinnacle" of her professional life. Ms Schramko, 72, had a long and distinguished career with the Red Cross and Smith Family but now works as a marriage and funeral celebrant while also working as a carer for her husband as he battles severe clinical depression.

Ms Schramko herself lives with bipolar disorder “with depression included” yet says she feels privileged to see the “miracles happening every day around the table” as a result of the CCOPPS programme.

Feedback from consumers and clinicians has been positive with one specialist mental health worker noting the peer worker had “achieved more with the consumer in a few weeks than I have been able to achieve in two years”.

Ms Green says the service is currently in the process of publishing the results of the program evaluation that, once complete, will provide a model for older people’s mental health services across the country.

“There is an emotional passion involved to make a difference to someone who is in this boat. We are not psychologists or psychotherapists or doctors of medicine. But we are people who have lived experiences who are able to say we have got through them. I think the most important thing we do is to give hope.” (Vicki Schramko)

John Walker - Central Coast older persons peer support worker

GETTING IN EARLIER

Changes in personal circumstances as people age can act as risk factors for emergence of mental health issues in older age, as well as exacerbate pre-existing mental health conditions. Potential risk factors include physical health problems, barriers to use of transport, including mobility, sight and hearing issues, social isolation, loneliness, bereavement and financial stressors.

Prevention and early intervention strategies are essential to optimising outcomes for people at risk of mental illness, regardless of age. Older people, particularly men aged 85 and over, are at particular risk of self-harm through suicide or self-neglect. Harm by others in the form of elder abuse also puts older people at risk. These risks represent important target areas for gains in mental health and wellbeing for older people.

Embedding prevention and early intervention

The value of prevention and early intervention in mental health applies to all age groups. Older people report that identification of a mental illness can be delayed due to a lack of knowledge of what mental illness can be like or what to do. One consumer told the Commission they were in denial about their mental illness until reaching 75 years of age. Another said it was not until they visited the Black Dog Institute's website that they recognised their experience in a description of depression.

Enhancing knowledge and understanding of the mental health issues in older age is key to promoting prevention and early intervention to assist older people to live well as they age, and to help carers understand when to seek support. Community and workforce education that supports the identification of mental health issues in older people and assistance with accessing appropriate care and support, are keys to successful prevention and early intervention. Mental Health First Aid (MHFA) training is a potential mechanism for education, with a MHFA course for older people currently under development[19] (see case study on page 22).

Older people with mental illness can have co-occurring complex care and support needs[20,21]. Specific areas of focus for prevention and early intervention include physical and mental health, cognitive function, nutrition, accommodation, finances, and social and personal relationships. In this way, early intervention works across the person's life needs, not just their health requirements.

Examples might include improved availability and access to social groups such as Men's Sheds, Country Women's Association, walking groups, community gardens, bush-care or participation in the University of the Third Age[22] (see case study on page 16) or volunteering for information, socialisation and enjoyable activities.

Many services already struggle to meet the needs of older people, too often focusing only on those who have become severely unwell[23]. Strategies for prevention and early intervention for younger people need to be extended to older people. This includes the availability of stepped-care options, particularly for mild and moderate conditions. Prevention and early intervention approaches need to be person-centred and tailored to each individual, as 'older people' are not a homogenous group. There may be merit in considering the needs of the 'young old' (65-74 years), the 'old' (75-84 years) and the 'very old' (85+ years). However, age alone should not determine the approach, it should be determined by individual needs.

Suicide prevention remains a priority for older people

In NSW, as it is across Australia, the highest age-specific suicide rate is in men aged 85 years or older (37.6 per 100,000)[24]. This rate is six time the age-specific rate for women of the same age (6.5 per 100,000) and nearly three times the rate for men aged 65-69 years of age (16.4 per 100,000)[25]. There are a number of risk factors for suicide in later life including depression, previous suicide attempts, serious physical illness, social isolation, loneliness, poor social support, concern about being a burden on loved ones and significant loss including bereavement.

Efforts to reduce the number of people who suffer suicidal ideation and behaviours are just as relevant in later life as they are for people when they are younger. These efforts are sometimes confused with the debate surrounding euthanasia, however suicide prevention is separate to discussions about a person's right to die. Specific strategies to prevent suicide in older people recognise the issues discussed above[26]. Suicide prevention needs to be multi-faceted and multi-layered and include optimal detection and management of depression[27]. The United Kingdom has reported a reduction in the suicide rates of older people and while the reasons for the drop are not fully understood, it serves as an example that reductions can be achieved[28].

The LifeSpan trial in NSW[29] identifies nine strategies that can be applied in parallel at a local or regional level to reduce the number of completed suicides. It advocates for tailored suicide prevention plans for older people and other at-risk groups. The trial is based on the internationally recognised "systems approach" to suicide prevention, which applies multiple interventions across a spectrum ranging from population-based public health measures through to medical interventions targeting the individual[30]. The trial – now in four sites in NSW – is a collaboration between the Black Dog Institute and NSW Health with the financial support of an independent philanthropic grant from the Paul Ramsay Foundation. LifeSpan addresses a whole of life suicide prevention approach.

The National Health and Medical Research Council and beyondblue have also partnered to promote research into depression, anxiety and suicide among older Australians and have advertised a Targeted and Urgent Call for Research, with a total of $5 million allocated[31].

Responding to elder abuse

There is a growing recognition of the abuse of older people by people in a relationship of trust with them, such as family, friends or others on whom they depend. Elder abuse can take many forms including financial, psychological, physical and sexual abuse, and neglect.

Elder abuse is a complex issue that can stem from multiple causes, such as family stressors, caregiving stress, and societal and cultural issues, including the stigma and discrimination people face as they age.

A higher proportion of older people who have experienced elder abuse suffer from depression or psychological distress than do their peers who have not experienced abuse[32]. This distress includes feelings of helplessness, alienation, guilt, shame, fear and anxiety.

In a 2017 opinion article, The Hon Dr Kay Patterson AO, the Age Discrimination Commissioner at the Australian Human Rights Commission, stated that 'the risk and incidence of elder abuse will become more critical as the baby boomer generation ages and home ownership for younger generations decreases, placing more pressure on transfer of wealth within families. There are already signs of increasing demand for elder abuse services. Despite positive steps taken by state and territory governments and non-government groups to address and raise awareness about elder abuse, the

issues are not simple and need a concerted effort to find solutions to reduce the risk of older people being victims of inexcusable abuse. The abuse and exploitation of our seniors is a human rights violation and it has no place in Australia'[33].

Although the NSW Government has committed to tackling elder abuse[34], there needs to be more effort in researching, conceptualising and measuring elder abuse and in service development that focuses on individual needs and preferences[35]. The Australian Law Reform Commission has recently released its report *Elder Abuse – A National Legal Response* which was tabled in the Australian Parliament on 14 June 2017. The report makes 43 recommendations for law reform to safeguard older people from abuse and support their choice and wishes, and should form the platform for national discussion of reform to reduce the incidence of elder abuse.

Nadia Rivero - member of the Spanish Speaking Community Choir, an initiative to engage older people with torture and trauma backgrounds in community activities.

CASE STUDY

Learning in the third age

The University of the Third Age (U3A) is a worldwide movement credited with helping more than 30,000 NSW based seniors maintain mental wellbeing through further education.

The University of the Third Age (U3A) is making a unique contribution to the physical and mental wellbeing of older Australians, according to international research.

Unlike traditional places of study, this 'university' requires no entry qualifications and brings with it few expectations in the way of examinations or assignments. Instead, this initiative, in which people aged over 50 are both teachers and students, flourishes at a community level in 69 locations across NSW. The largest, which is in Sydney, has 6,500 of the 30,000-strong NSW membership base.

In some locations, U3A offers in excess of 400 courses each semester yet asks only for an average fee of just $50 per person per annum in return, largely because most of its services are provided on a voluntary basis.

The U3A concept was originally devised by French professor Pierre Vellas to allow people aged between 50 and 90 to take part in university courses free-of-charge and without academic credit. The Australian U3A, based on a UK adaptation, is a community-based, self-help model where the skills, interests and abilities of the members themselves form the curriculum. For example, if a member has yoga skills they might teach a class, a card player might teach bridge or a retired English teacher might start up a course in poetry appreciation.

U3A Network NSW president Ainslie Lamb says despite differences in their size and scale, all U3A network locations are united in their goal to offer a range of activities in a friendly supportive environment while "encouraging social interaction and forming new friendships" with like-minded individuals.

Owing in part to the flexibility of its programs, the mental stimulation provided by the U3A model has been credited with assisting seniors involved in the organisation to maintain both physical and mental wellbeing.

In a 2009 paper entitled *Membership of the University of the Third Age and perceived well-being*, researchers from the University of Sydney's Faculty of Health Sciences undertook a survey assessing eight health concepts: limitations in physical activities because of health problems; limitations in social activities because of physical or emotional problems; limitations in usual role activities because of physical health problems; bodily pain; general mental health; limitations in usual role activities because of emotional problems; vitality; and general health perception of 975 U3A members based in the Greater Sydney Metropolitan Region. Comparisons were made with groups of older people from the US, and the U3A sample scored as well as, or better than their American peers. Their report concluded that members of U3A "had better-than-average general, physical and mental health, and that membership of U3A can, even in the very elderly, assist in conferring a much more positive perception of well-being".

Ms Lamb says there are also many anecdotal accounts of members who have found that being part of a U3A has helped them overcome feelings of grief, depression and isolation as they have found new friends and constructive activities to participate in and contribute to.

Ms Lamb says while each branch is autonomous, U3A branches cover a wide range of interests, ranging from current affairs and philosophy to creative arts and bushwalking. In addition, many U3As regularly offer exercise programs such as tai chi and yoga as well as encouraging good nutrition and wellbeing generally.

> *"They have found purpose in being accepted for themselves, in being respected for their opinions, in being able to offer curriculum contributions, and in being involved in group activities such as choirs or creative writing workshops." (Ainslie Lamb)*

The U3A also encourages members to be involved in health research conducted by traditional universities, through participating in online and face-to-face surveys, and in some instances acting as 'patients' for medical students.

Ms Lamb says the fact the programs are organised, administered, paid for and delivered by their own membership helps seniors in NSW to lead full and productive lives while at the same time promoting self-reliance, self-confidence and a positive outlook.

Sapphire Coast cooking class, U3A

PUTTING PEOPLE FIRST

Being able to take charge of one's own health and wellbeing is an important component of good physical and mental wellbeing. An absence of self-agency, as well as scepticism about recovery from poor mental health for older people, can negatively impact on their outcomes. Similarly, a lack of recognition of the unique care needs and concerns of older people and those of their carers represent important opportunities to improve mental health and wellbeing outcomes.

Promoting self-agency

Historically, services for older people have tended to assume that the service knows what is best, and have adopted a caretaker role on behalf of the older person. This has been exacerbated by stigma around the idea that mental illness means that once a person is diagnosed they become incapable of rational choice. As a result older people may not always be asked about their lives or their recovery goals, or supported to direct their own care[36].

When self-agency is reduced, or the ability to make decisions is reduced, the skills and strengths of older people can go untapped and unrecognised. In turn, this has been linked to poorer health outcomes[37]. Self-agency can be enhanced through education about mental health issues, consumer rights and responsibilities and available supports and services. Content and format of education needs to be responsive to the needs of older people and their carers.

The participation of older people with mental illness in service planning, policy and research is critical to service success, yet their inclusion is under-developed[38] in comparison with the participation and engagement of younger age groups[39].

Older people said that they often fear losing their independence and "ending up in a nursing home or hostel". This fear can further impact on their own sense of self-agency and on their help-seeking behaviour. Partnerships between older people, health and aged care services and community services need to be improved to support the older person being the driver of their care and treatment and to use their skills and strength. Promising examples of collaborative care models for older people with mental illness include mental health-residential aged care partnerships implemented through the NSW Ministry of Health's Pathways to Community Living initiative (PCLI)[40].

Pathways to Community Living

This initiative arose in response to action called for in *Living Well* and evidence that people with severe and enduring mental illness experience better quality of life and improved health and social outcomes if they can be supported to live in the community, in an environment that they can call home, and that provides opportunities to engage with the community.

It is a person-centred and recovery-oriented approach with consumer led care and tailored assessment, planning, transition and support processes for each person wishing to transition from long term hospital care to community living.

Substantial work has been undertaken by the NSW Ministry of Health and Local Health Districts to enable long stay mental health patients to return to live in the community with appropriate supports and for mental health-residential aged care partnerships to deliver specialist residential aged care services for these long stay older consumers with mental health and aged care needs.

Recovery-informed policy and practice

The intention that specialist mental health services work with people towards their self-defined personal recovery (or enablement, as it is referred to in aged care services), has gained momentum over recent years. However, the concept of recovery for older people is often fraught by ageism.

The wrongly held notion that being old means that recovery is not possible, or that age means diminished opportunity to live meaningfully or contribute, works against positive health outcomes for older people. The mental health care of older people who are terminally ill, have cognitive impairment or have chronic incurable illness, should have a recovery/enablement approach.

Intrinsic to personal recovery is hope, and services may not always hold high hopes or expectations for older people who experience mental illness. If a sense of hope is absent, and if older people are not supported to see the possibility of a contributing future, then older people may question the point in trying, and their health and wellbeing suffers. An example of a systemic approach to this issue is the NSW Ministry of Health's implementation of a recovery-oriented practice improvement project in its Specialist Mental Health Services for Older People (SMHSOP)[41]. SMHSOP services are community based multidisciplinary services for people over the age of 65 who may be experiencing issues with their mental health. The services offer consultation and education to families and carers, and to other service providers including GPs, residential aged care staff and agencies supporting older people in the community (see case study on page 30).

Recovery-oriented care needs to be person-centred and tailored to the individual. Recovery is unique to each individual. Recovery in older people may need a different approach to that of young people. For instance, recovery for older people may mean maintaining their identity, rather than the creation of a new identity. Maintenance of self-identity and history in a nursing home setting can be assisted by practices such as the use of reminiscence therapy and a personal memory box.

Families and carers

Many older people have a significant role in caring for others. In NSW there are an estimated 197,000 carers aged 65 and over who are providing care to a spouse, child, grandchild or other family member or friend who has a disability or chronic health condition[42].

The intensity of caring work can have a range of impacts, and older carers may face challenges to their health and wellbeing. A recent survey undertaken by Carers NSW found that 35 per cent of carers over the age of 60 reported high or very high levels of psychological distress, with a further 30 per cent reporting moderate levels[43]. Reports from older people during consultation with the Commission indicate that the demands of caring, coupled with their own mental health care needs, can lead to isolation, increased loneliness and poorer outcomes for the carer's own mental health. Older carers also have the worry about what will happen to their adult children or partner when they no longer have the capacity to care. Aboriginal people who are elders often face particular pressure to look after members of their community, and this can create physical, emotional and financial stress[44].

It is important that older carers are able to focus on their own needs and receive support including respite, but this is often hard to obtain. To promote wellbeing for older people, an assessment of needs should identify caring roles, consider carers' capacity to undertake the role, and include the development of carer support plans.

The role undertaken by families and carers in supporting older people with mental illness is often unrecognised, and under-valued. Caring for someone with a mental illness is different to other caring roles, as carers can experience additional challenges, including social stigma. Younger people with a

lived experience of mental illness, who care for older people, also experience discrimination in their caring role. They report that their views are sometimes dismissed as a result of their mental illness, and they are cut out of decision making.

It is crucial that mental health services recognise the important role of family and carers, and link carers to the support which will enable them to maintain their own health and wellbeing.

Advance care directives and end of life plans

People living with severe mental illness can have a reduced life expectancy of around 25 years, which for them reduces the generally accepted definition of older age as commencing at 65 years, potentially down to 50 years. This 'early old age' means that advance care directives and end of life plans may need to be documented at a relatively young age, and include discussion regarding power of attorney issues.

Health professionals are legally required to respect the wishes of consumers detailed in these plans, however people with a mental illness often report that directives and plans are not adhered to. This can be true when a person presenting with the symptoms of mental illness is assumed not to have been a competent decision maker at the time of developing the advance care directive or end of life plan. These attitudes may relate to the stigma and discrimination that is associated with both mental illness and ageing. This demonstrates a need for workforce education on consumers' legal rights and how to support informed decision making by older people experiencing mental health issues[45]. The United Nations Human Rights Convention Article 12 reaffirms equal rights of all people before the law[46].

Care affordability

Getting older usually leads to a reduction in income which can impact on service access and receiving care. It is estimated that 80 per cent of older Australians will be eligible for at least some of the age pension over the next forty years or so[47], which illustrates the constrained financial situation of many older people. Data from the Organisation for Economic Co-operation and Development (OECD) indicates that the age pension leaves one in three older Australians living with an income that is less than 50 per cent of the median household disposable income[48]. Living in poverty not only compromises the ability for an older person to seek and receive the care they need, it also adds to the stress and complexity of living with a mental illness and/or caring for someone with a mental illness.

Low income was reported by older people who were consulted by the Commission as being a significant difficulty in living well and accessing the care they need. Recognising and finding ways to remove some of the barriers to service access that poverty can cause should be an important consideration in service design and delivery.

Bryce Gunn and Terry Kemp, residents of Greenway public housing estate who work as volunteers to improve the welfare and wellbeing of their community.

CASE STUDY

Mental health first aid for the older person

A lack of clear guidance on how members of the public can best support older people with mental health problems has prompted the introduction of a new training course for the general public.

Betty Kitchener believes each and every senior Australian deserves to live a full, active and healthy life.

Yet the founder of the internationally renowned organisation Mental Health First Aid (MHFA) Australia says mental health problems in those aged 65 or over are neglected - frequently attributed to general ageing or poor physical health The lack of understanding can add to the increasing feeling of vulnerability already felt among this burgeoning population.

Ms Kitchener argues that a failure to recognise mental health problems in older people, together with the stigma of these problems and a lack of supportive interactions with family and carers only compounds the issue.

In an attempt to redress the balance, the organisation she co-founded will shortly introduce a 12-hour course that aims to train the community to proactively respond to older people with mental health problems - rather than waiting for a mental health crisis before taking action.

The Mental Health First Aid for the Older Person Course will be a face-to-face course delivered over four sessions of three hours each.

The curriculum is based on expert-consensus guidelines developed through the Delphi method, drawing on the expertise of both mental health professionals and people with lived experience of mental health problems. The course includes practical videos, PowerPoint presentations, interactive exercises and discussions.

The course, which includes tips on how to assist a person who is confused or developing dementia, also teaches participants how to apply the MHFA ALGEE action plan – to:

- **Approach the person and assist with any crisis**
- **Listen and communicate non-judgmentally**
- **Give support and information**
- **Encourage the person to get appropriate professional help**
- **Encourage other supports.**

The training takes a holistic approach which includes an examination of issues like dementia and cognitive impairment which may co-exist with mental illness in some older people.

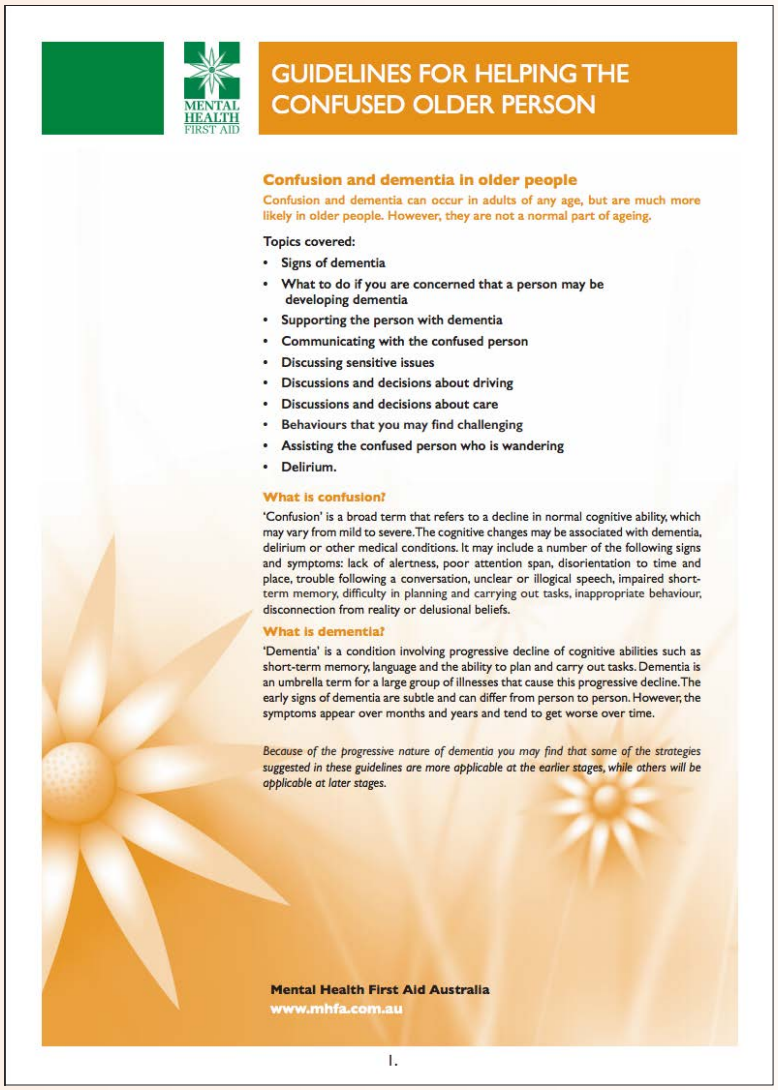
Each participant will receive training on how to communicate with an older person who has a mental health issue. The topics include gaining and keeping the person's attention, being understood during a conversation, communicating in a group situation, asking the person questions, offering the person options, non-verbal communication and challenges during communication.

In addition, they will also receive a 185-page manual incorporating additional information about topics such as how to help an older person with gambling problems and factors that need to be considered when providing mental health first aid to an older Aboriginal or Torres Strait Islander person, as well as older people who identify as LGBTI (lesbian, gay, bisexual, transgender or intersex).

Ms Kitchener, who has retired as CEO of MHFA Australia, but is continuing as a consultant to pilot the new course, said that while MHFA courses have been tailored for various stages of the lifespan and for various cultural groups, there has not been specific adaptation to assist older people.

The pilot courses will be rolled out across Victoria first and later expanded to other areas across Australia. MHFA Australia plans to conduct two instructor training courses during 2017, with the first of these taking place in early October.

"The major barrier against this tailoring was the need to have guidelines on how to assist people who are developing dementia, cognitive decline or in various crisis situations associated with confusion," (Betty Kitchener)



GUIDELINES FOR HELPING THE CONFUSED OLDER PERSON

MENTAL HEALTH FIRST AID

Confusion and dementia in older people

Confusion and dementia can occur in adults of any age, but are much more likely in older people. However, they are not a normal part of ageing.

Topics covered:

- Signs of dementia
- What to do if you are concerned that a person may be developing dementia
- Supporting the person with dementia
- Communicating with the confused person
- Discussing sensitive issues
- Discussions and decisions about driving
- Discussions and decisions about care
- Behaviours that you may find challenging
- Assisting the confused person who is wandering
- Delirium.

What is confusion?

'Confusion' is a broad term that refers to a decline in normal cognitive ability, which may vary from mild to severe. The cognitive changes may be associated with dementia, delirium or other medical conditions. It may include a number of the following signs and symptoms: lack of alertness, poor attention span, disorientation to time and place, trouble following a conversation, unclear or illogical speech, impaired short-term memory, difficulty in planning and carrying out tasks, inappropriate behaviour, disconnection from reality or delusional beliefs.

What is dementia?

'Dementia' is a condition involving progressive decline of cognitive abilities such as short-term memory, language and the ability to plan and carry out tasks. Dementia is an umbrella term for a large group of illnesses that cause this progressive decline. The early signs of dementia are subtle and can differ from person to person. However, the symptoms appear over months and years and tend to get worse over time.

Because of the progressive nature of dementia you may find that some of the strategies suggested in these guidelines are more applicable at the earlier stages, while others will be applicable at later stages.

Mental Health First Aid Australia
www.mhfa.com.au

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BETTER RESPONSES

Health system responsiveness requires service integration and appropriate funding models. To aid recovery oriented care, services need to be community oriented and barriers to service access need to be reduced. Mental health care should also be delivered where it is needed, including residential aged care facilities where there is a high demand for such care. The unique needs of older people in regards to safe medication use, reducing social isolation, appropriate housing, as well as chronic illness and dementia, are all considerations of a responsive mental health care system.

Integrated care and funding mechanisms

The funding arrangements for care for older people are an impediment to integrated care as they are frequently fragmented across health, mental health and community services and funded from different sources.

State government is responsible for meeting the health needs of older people through the delivery of services in public hospitals and community mental health and health centres, while the Commonwealth Government funds GP services and other forms of primary care, residential aged care services and aged care packages in the community, as well as medications and private consultations through Medicare with psychiatrists and psychologists.

The community-managed sector provides most residential services, as well as community support services such as: accommodation support; employment and education; leisure and recreation; family and carer support; self-help and peer support; counselling services; promotion, information and advocacy. There is also private sector involvement in hospitals and aged care, while local governments fund a range of social support services.

The current planning, funding and service delivery structures are inflexible and often do not assist with the delivery of integrated care to meet older people's complex and continuing needs.

This fragmentation has resulted in most nursing home residents unable to access Medicare-funded psychological care due to specific exclusions in the Aged Care Act and Medicare regulation [49, 50]. Older Australians living in nursing homes have some of the highest rates of depression and anxiety, and this exclusion constitutes systemic neglect and a denial of human rights involving discrimination on the basis of age and infirmity[51]. There have been calls for urgent action due to the "complete absence of any positive and mandatory legal obligation on the part of facilities to take proactive measures to promote (the) mental health and wellbeing of their residents"[52].

Concerns have also been expressed to the Commission about other perceived care inequities for older people. This feedback was provided in the context of the Commission's 2016 community survey on the implementation of *Living Well*[53]. The main concerns related to aged care initiatives, such as *My Aged Care*, and the NDIS, which were reported as not being inclusive of mental health care or care for older people:

"Older people (over 65) can't access NDIS, only My Aged Care, and there is a lack of understanding around mental health (particularly depression and anxiety in the over 65 cohort)".

"(The) ability to access and wrap services around this population is significantly difficult if not impossible due to the significant gaps between NDIS and My Aged Care and the inability to access effective psychosocial support for those whose physical function is not impaired yet require recovery oriented community services".

Service gaps

Older people benefit from a range of services and supports that address their mental health, physical health and social support needs, including daytime activities, intimate relationships and social connections. Rarely are these services provided by one organisation and frequently there are gaps between the services that are available, particularly in remote, rural and regional areas. There is benefit in identifying and addressing gaps, along with opportunities for enhanced collaboration and integration of services. Sadly there is a lack of specialised skill and capacity in many services. There can also be a bias against older people when prioritising access to general mental health programs.

A number of initiatives have been developed in response to concerns about fragmented services. The NSW Ministry of Health is implementing the NSW Integrated Care Strategy[54] which has a person-centred focus and aims to improve the experience and outcomes of care.

Three demonstrator sites are implementing the strategy: Central Coast, Western Sydney and Western NSW, with all sites incorporating vulnerable older people with complex and chronic conditions. Western NSW will also be addressing complex and enduring mental health, drug and alcohol conditions. The strategy is being implemented during 2014-2017, with monitoring and evaluation occurring during and after the implementation phase.

HealthPathways[55] is another innovation aimed at reducing fragmentation, and is being implemented across NSW to enhance clinical skills, knowledge and use of available services. The initiative was developed in New Zealand and consists of an online portal used by clinicians to facilitate assessment, management and referral decisions for a range of health conditions. Each Local Health District and PHN partnership is expected to tailor the content of the initiative to reflect local arrangements and expert opinions, with local professionals such as GPs, specialists, nurses and allied health providers involved in development. The target audiences are general practitioners and other health professionals who are managing patients in the community and wish to initiate referrals to hospital or request specialist assistance. Some of the districts are working on incorporating mental health and drug and alcohol services and practice decision supports into their local initiative.

Another initiative that aims to enhance access to appropriate care is the WayAhead Directory[56]. The WayAhead Directory is a comprehensive online database used to find local services, to make referrals and access mental health information and resources. It addresses the whole of life span and provides information on services providing care to older people. The resource is intended for use by people living with a mental health condition, carers, service providers, health care professionals and the general public.

While these and other initiatives facilitate access to available services, service gaps still need to be addressed. Services need to work together to ensure that the needs of older people and their families and carers are met. Coordination of services requires information sharing, transparency and agreed care pathways between key providers of health care, mental health and aged care services including general practitioners, residential aged care facilities and non-government organisations. Equity in access and outcome for older people, their families and carers and service providers is imperative. Feedback from consumers and their carers is key to ensuring accessible and responsive services.

Shift to community

Comprehensive care and support services are required to meet the complex care needs of older people with mental health issues. There is currently a lack of community care options to support older people with chronic mental illnesses. This places them at greater risk of hospitalisation, homelessness or placement in residential aged care. This situation also places unnecessary additional stress on carers and families. Access to care is particularly challenging for older people who are disconnected from their family, friends and carers.

Older people have identified a number of gaps in current community supports including a lack of social activities, support for relationships, and services that meet alcohol, other drug and physical health care needs. Commitment to addressing the barriers that impact access to community care services such as transport, stigma, workforce capacity and funding of community services is required.

Build the capacity of services to respond therapeutically

An area requiring special focus is the provision of mental health services to older people in residential aged care facilities. Of those people in permanent aged care, over half of all residents were reported to have mild, moderate or major symptoms of depression[57].

Despite the efforts already made to provide person-centred care to residents there is evidence of overprescribing of psychotropic medication[58], under-recognition of depression[59], and need for specific training for staff to address the complex care needs of older people with mental illness[60]. One challenge for staff in residential aged care is the under-provision of services from both specialist and primary care to support them in the provision of care and treatment.

Many people with a lived experience of mental illness have experienced trauma in their lives[61]. For some, this trauma may have occurred whilst in care in mental health facilities or other institutions. Consequently, entering a residential aged care facility can be re-traumatising to an older person. The fear and resistance to being “placed” once more into residential care must be acknowledged and respected and efforts made to facilitate their psychological adaptation and minimise stress.

A focus on capacity building within residential aged care facilities is crucial. It is also important that staff are trained to meet the mental health care needs of residents and that service design, including the built environment, is not counter-therapeutic.

Medication and polypharmacy

Concerns have been expressed about over-reliance on medication for the management of mental health issues in older people[62], with older people shown to be less likely to see a psychologist or a psychiatrist. When they do see a doctor for their depression, they are more likely to receive medication for that[63]. Person-centred care requires that treatment approaches reflect evidence-based care, and the needs, wishes and circumstances of the individual.

Prescribers need to be mindful that changes to the body naturally associated with ageing can increase the risk of medication causing harm. For example, medication may have a more prolonged effect on the body than in a younger person, so older people generally need lower doses[64].

Older people living with a mental illness often take medication for a range of age-related health problems at the same time as taking medication for mental illness. Multiple medicines, or

polypharmacy, is a significant risk factor for adverse medication events and poor outcomes in medication use[65].

In consultations undertaken for the Commission's *Medication and mental illness* paper[66] lack of communication between service providers, and the resulting negative impact on continuity and quality of care, was seen to contribute to this issue:

"One of the challenges is the co-morbidities of old age - which can include cardiac, metabolic, skeletal and psychiatric issues - and the arsenal of prescription medications that comes with them. This is often accompanied by specialists working on the left hand and not interacting with or knowing what the prescribing specialist on the right hand is doing. They are not aware of or mindful of the possible contraindications, drug reactions or the testing that may be required."

For some older people the high cost of medication can be a barrier to access, particularly when there are numerous medications to purchase.

There is growing concern that psychotropic medication is over-prescribed for older people, and used not just to treat mental illness, but sometimes as a means of managing challenging behaviour[67, 68]. Although it varies between aged-care facilities, about half of people in residential aged care facilities and up to 80 per cent of those with dementia are receiving psychotropic medications, with evidence to suggest that in some cases these medications are being prescribed inappropriately[69]. It is important that staff in aged-care facilities are educated in the safe and appropriate use of medication, along with non-pharmacological management of behaviours including simple analysis of causes of behaviours and ways to address those causes.

Another concern is the use of alcohol by older people, and its effects in tandem with medication use. Patterns of alcohol consumption in Australia indicate that while older people are less likely to binge drink, they are the most likely age group to be daily drinkers[70]. The negative health effects of alcohol increase with age, including liver and cardiovascular disease, acquired brain damage and early onset dementia[71]. In addition, age-specific potential harms such as increased medication interactions and risk of falls and social isolation are also exacerbated[72].

Social isolation and loneliness

Although it is difficult to gain a true estimate of the prevalence of chronic social isolation and loneliness among older people, Australian and international research indicates that a conservative estimate for people aged over 65 years is between seven per cent and 10 per cent[73] with some research indicating it is as high as 43 per cent[74].

Older people are more likely than younger people to suffer loss of their physical independence and death of a spouse and hence more likely to face isolation and loneliness. Research indicates a range of negative outcomes for the health and wellbeing of people who are socially isolated and lonely, including all-cause mortality[75] and poor mental health[76]. Evidence also indicates that having a mental illness may lead to difficulties in establishing and maintaining informal social ties throughout the life course into older age[77]. Older people with a mental illness therefore are particularly vulnerable to social isolation and at a time when social support is most needed.

Early assessment of social isolation in older people, and referring on individuals who could benefit from engaging with community support services such as Senior Citizen Centres and Neighbourhood Centres, would help mitigate the health and wellbeing risks associated with loneliness. A system level approach that strengthens social inclusion of older people within the community is also required. This might include facilitating volunteer opportunities for older people and building organisations

that are more inclusive of older people. An example of a system level approach is the Campaign to End Loneliness in the United Kingdom[78]. The initiative is a network of national, regional and local organisations and people working together through community action, good practice, research and policy to ensure that loneliness is acted upon as a public health priority at national and local levels.

In 2015 the Australian Human Rights Commission undertook a National Inquiry into Employment Discrimination against Older Australians and Australians with Disability, with the *Willing to Work* report[79] released in May 2016. The Inquiry heard of the widespread nature of discrimination against older people in employment, as well as distress, poor health and poverty experienced by individuals unfairly excluded from paid work due to age and disability discrimination. The *Willing to Work* report contains a range of recommendations intended to address these issues and enhance opportunities for workforce participation. Employment is a source of social connection, meaningful work and income, which together can combat the social isolation and affordability obstacles to participating in one's community.

Physical health and mental health

Having a chronic illness, such as diabetes, heart disease, or arthritis is one of the strongest risk factors for depression and anxiety[80]. This is compounded by reduced physical mobility, poor physical health, and chronic illness as the body ages. According to some older people consulted by the Commission, having a physical disability such as arthritis can impact on their ability to engage socially, with this negatively impacting their mental illness.

People who have a lived experience of severe mental illness are likely to die up to 25 years earlier than the general population from conditions such as respiratory or cardiovascular diseases caused by medication side-effects, obesity, smoking, and a lack of exercise[81]. This means that 'later life' for people with severe mental illness arrives earlier.

Identifying, monitoring and supporting the physical health needs of older people with mental illness is crucial, and yet the health system is not always organised in a way that supports an integrated response. Opportunities to detect mental illness or physical illness early, or sometimes at all, are missed, and older people live with symptoms that might be avoided.

Mental health and dementia

The relationship between dementia and mental illness is complex. Eighty per cent of people over 80 years of age do not have dementia[82], but 40-50 per cent of people with Alzheimer's disease have been reported to experience symptoms of depression[83].

The symptoms of dementia and depression, including withdrawal from social activities and general apathy, can be similar to mental illness, which can lead to misdiagnosis. In addition, a dementia diagnosis frequently results in the failure to recognise mental illness, especially depression.

Being a carer of an older person with dementia can be demanding. Families and friends who care for someone living with dementia are at increased risk of depression, anxiety, and physical illness[84]. Sometimes an older person cares for another older person, such as their partner, with dementia. Appropriate care and support is needed to ensure the mental health and wellbeing of both parties.

Housing and homelessness

A home provides everyone with a sense of belonging and security. Access to stable and affordable housing is an issue for many people with mental health problems, regardless of age, and there is some evidence that mental health problems develop as a result of homelessness[85].

People living with a mental illness generally have greater difficulty in accessing and keeping a home due to lack of support, decreased income, the impact of reduced physical functioning and challenges in accessing suitable supported accommodation.

For many older people, changes in their physical and mental health needs may result in them being unable to live independently and having to accept accommodation that is not what they want and removes them from their social supports and local communities. These transitions can have a negative impact on their mental health.

Increased availability of affordable housing that is appropriate to older people is critical whether they are living with a mental illness, are the primary carer for someone or to support their general health and mental wellbeing, particularly in rural and remote areas. Wrap-around supports, such as those provided through supported accommodation models, are also essential for older people with mental health issues to live well in their community.

CASE STUDY

Mental health recovery for older people

A new state-wide initiative will see the adoption of a more holistic approach to assisting older consumers of mental health services.

By 2026 the number of older people in NSW who experience some form of mental illness is projected to hit 300,000.

While that statistic may seem alarming to some, Dr Kate Jackson, who leads the NSW Ministry of Health's Older Peoples' Mental Health Policy Unit, says that contrary to common perceptions, later life is a time of improved mental health for many people, and the proportion of people with diagnosable mental illness actually reduces in later life.

She argues mental health therapies are as effective in older people as in younger people, and older people who experience mental illness, whether newly-diagnosed or long-term can experience improved mental health with the right treatment and management.

Despite this, research suggests that compared to their younger equivalents, older people often have more complex care needs, may respond differently to medication and frequently require a longer time for clinical recovery.

In an attempt to more adequately address the needs of this older consumer group, the policy unit has developed a new initiative that focuses solely on what recovery means for older people with mental illness.

Called the Older Peoples' Mental Health (OPMH) Recovery Project, this statewide initiative has seen 12 Local Health Districts develop 16 separate local practice improvement projects using existing resources.

> *"Mental illness and dementia are not an inevitable part of becoming older." (Dr Kate Jackson)*

The diverse range of projects incorporates the development of an OPMH peer workforce, recovery-oriented group programs, recovery-oriented practice training, and collaborative wellness planning and care planning with consumers of mental health services.

Dr Jackson says the approach includes clinical treatment to assist in improving symptoms, but also understanding and supporting a person's individual recovery goals, as well as promoting their identity, independence, sense of hope and social connectedness.

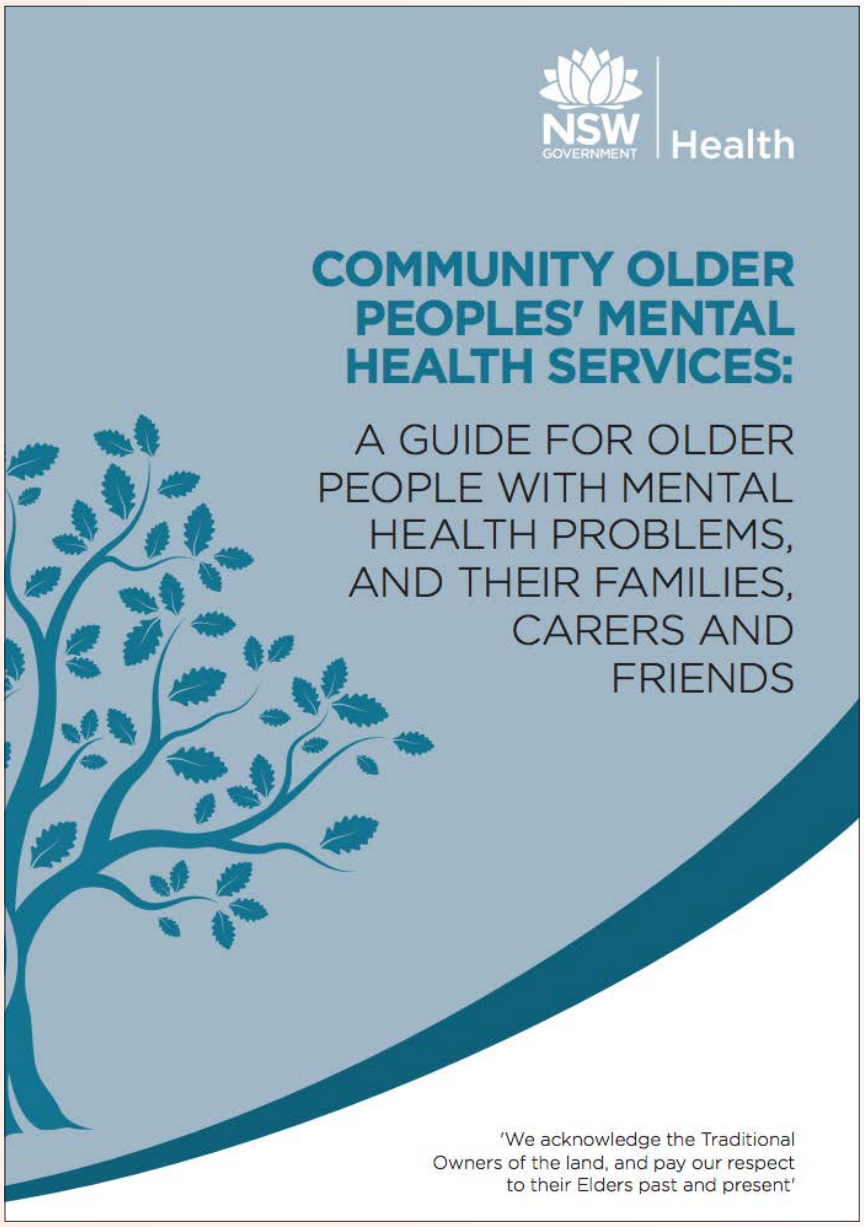
There is substantial published evidence that supports the positive impacts of recovery-oriented practice on hope, optimism, independence, coping skills, wellbeing and quality of life, as well as mental health symptoms.

But there is currently limited data and published evidence about the impacts of recovery-oriented practice specifically in older people with mental illness.

The NSW OPMH Recovery Project is expected to significantly add to the evidence base.

Dr Jackson says preliminary feedback from consumers and carers on the various local OPMH recovery projects has been "extremely positive", and many of these projects will publish their results, including consumer measures of the impact of the projects.

"Recovery is just as relevant for older people as for younger people, even though older people may have different perspectives on what recovery means for them. Recovery-oriented practice is about clinicians working alongside older people with mental illness to support them in their recovery journeys." (Dr Kate Jackson)



CARE FOR ALL

Older people, like their younger counterparts, have their unique individual identities, cultures and personal trajectories that may impact on their mental health in older age. A person-centred approach that respects the needs of different community groups is therefore crucial to ensure their needs are met appropriately and are respectful of their culture or traditions. Service planning should also take into account the needs of older people in rural and remote areas who may not have the same access to services as those living in major cities.

Lesbian, gay, bisexual, transgender and intersex (LGBTI) mental health

Older people who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) are likely to have had their identity shaped in times of significant homophobia and transphobia and to have experienced discrimination. They are also more likely to have poor mental health and higher use of alcohol, tobacco and other drugs[86]. Fear of discrimination may act as a barrier to accessing appropriate aged care and may contribute to social isolation due to fear of disclosing their sexuality[87]. While they may have lived in a supportive community or in a relationship, they may have to relocate in older age to a less accepting community or residential aged-care facility, where they may experience discrimination[88].

Access to LGBTI inclusive services that do not discriminate and have mental health and aged care workforces trained to be sensitive to the LGBTI community's needs are required to enable this community to have their sexuality, sex and gender identity accepted, especially as they age[89]. Experts consulted indicated that strategies that promote community development, the development of local online support networks and age-friendly community services and housing choices are required to better meet the mental health needs of LGBTI older people.

Multicultural NSW

Addressing the mental health needs of older people from culturally and linguistically diverse (CALD) backgrounds requires specific attention to the cultural beliefs and values relating to mental health for individuals, groups and communities. First generation Australians may experience delayed grief from their loss of their homeland. Older refugees, including survivors of genocide, can experience delayed post-traumatic stress as they age. These issues may not have been addressed previously and may lead to depression.

The difficulties for older people from CALD backgrounds can be exacerbated by poor English skills and lower levels of education. Some people may lose acquired English skills through dementia and may revert to a language that is not familiar to the people who are caring for them. This can lead to difficulties in communication, frustration and grief. People with dementia and their carers may become socially isolated if their friends and peers find it uncomfortable dealing with the person's changed behaviour and capacities.

This can be compounded considerably in CALD communities if there is stigma and embarrassment attached to both dementia and mental illness, with this potentially resulting in reluctance to use formal services[90].

Strong collaborations between mental health services and multicultural sector organisations and diverse communities must be developed to respond successfully to the needs of older members of CALD communities.

Rural and remote NSW

The ageing of the population is more marked in rural and remote areas than in metropolitan NSW[91]. Young people tend to leave rural and regional areas to pursue work, study and other experiences while older people either return or move to these areas to benefit from the positive aspects of coastal and country life. Despite the increase in older people living in these areas, the services to support them, including aged and community services, and community infrastructure that counters social isolation, have not grown accordingly[92]. There is also a more acute shortage of health professionals in rural and remote NSW[93]. These combined gaps pose significant challenges to accessibility of appropriate services and resources, with lack of transport compounding these difficulties. These shortages adversely impact on the continuity and quality of available care, affecting older people's capacity to continue to live at home and their access to timely assessment of and response to their mental health and wellbeing needs.

Cabramatta, NSW

SUPPORTING REFORM

Supporting reform requires investment in training, innovation and staffing resources. Specialist training in older people's mental health and the development of innovative ways to build and retain the workforce, such as developing the peer workforce, are important steps in progressing mental health reform.

Investing in our workforce

Health professionals and other staff in the mental health, aged care and community support sectors working with older people with mental illness and their carers and families, require specialist training in old age mental health to ensure they are adequately skilled and experienced in addressing the psychological, physiological and social impacts of ageing. This needs to be backed up by professional standards and competencies. A major challenge is the recruitment and retention of the workforce with skills and a genuine interest in older people's mental health. Staff turnover and recruitment of suitably qualified and skilled staff is an ongoing problem for services, particularly in residential aged care[94].

The resources to secure a stable and competent workforce in the future will require government commitment, along with regulation on skill mix and staff ratios in the residential care sector.

Training and education are required to improve attitudes and increase awareness and understanding of how to support and enable older people with mental illness. Services must have the capacity to provide holistic care which includes: viewing a person as a whole; conducting assessments across health, mental health and ageing issues; working with and supporting individuals who do not acknowledge they may be experiencing mental illness; and promoting positive ageing.

Continued effort to enhance the skills and knowledge of general practitioners regarding mental illness in older people is also required, given their pivotal role in providing care to older people, including those in nursing homes. Other health professionals, such as community pharmacists, also need to be supported through education to facilitate their roles in providing healthcare advice and support, and educating customers on health promotion, disease prevention and the proper use of medicines. Education needs to be inclusive of the identification of mental health issues in older people and assistance with accessing appropriate care and support, with Mental Health First Aid training a potential mechanism for supporting such 'gatekeeper' roles.

Benchmarking of services against evidence-based principles, practices and outcome targets is also a mechanism for promoting and supporting quality improvement. An example of this is the NSW Ministry of Health's Specialist Mental Health Services for Older People (SMHSOP) benchmarking initiative. The initiative has been implemented since 2007 and is a key mechanism for promoting quality improvement in SMHSOP community and inpatient services across NSW through the use of performance based data and reporting[95]. A national review of accreditation standards in the aged care sector is currently being undertaken by the Commonwealth Government, including a review of assessment performance[96].

Peer workforce

Employing people with lived experience of mental illness in peer worker roles has been found to produce a range of benefits to individuals, services and the workforce[97]. Older people report that older peer workers, because they may have similar life experiences, are better able to help them to identify ways of living that promote recovery. According to older people, the benefits of having the unique contact and support with an individual who understands what it is to live with a mental illness is invaluable.

While recruiting older people as peer workers has some logistical challenges in relation to working age and recruitment processes, their value and unique contribution to older people and their families and carers cannot be underestimated. The development of peer worker models in older people's mental health should be pursued. An example of older people peer workers is the Central Coast LHD's Older Person's Peer Worker Project. The Project has employed seven peer workers, with both the peer workers and patients benefiting from the Project[98].

See case study on page 10.

Sandy Degrassi, peer educator, South East Sydney Local Health District

A STATEMENT OF PRINCIPLES

1. Promote prevention and early intervention in later life

The physical and social changes that come with ageing can leave older people vulnerable to poor mental health. Enhancing our knowledge and understanding of factors that protect against poor mental health is key to prevention. Mental health promotion targeting older people should be available across NSW. Early intervention is needed when a person's mental health first starts to deteriorate, no matter what age they are, to halt progressive deterioration and avert the need for crisis intervention. Treatment for mental illness should be based on clinical and support needs and not on age. Person-centred, trauma-informed, recovery-oriented practice applies equally to older people and needs to be the foundation of their care.

2. Eliminate ageism and related stigma and discrimination

Many older people are vibrant, active members of the community whether they are living in their own home, receiving community-based services or living in residential aged care. However, the images and language used to describe older people frequently present negative stereotypes and generalisations. Age discrimination needs to be eliminated at personal, interpersonal and structural levels. The exclusion of most nursing home residents from Medicare-funded psychological care is one potent example. We need to counter stigma and discrimination with positive expectations, images, examples and objective data. We also need to counter discrimination by ensuring equitable access to mental health care and support. Positive attitudes and behaviours towards older people can improve with education and understanding.

3. Increase participation of older people in the decisions which affect them

The desire and ability of older people to exert choice and control over their own care should be respected. We need to move away from doing things 'for' older people to doing things 'with' older people. Health, community and aged care services should involve older people and their carers in planning, implementing and evaluating services. Workforce training on supported decision making needs to be made available. Robust models for consumer and carer participation should include older people. Advance care planning needs to be offered and supported, including assistance in appointing a power of attorney where needed.

4. Increase ageing-friendly, culturally informed and accessible services and information

Older people have their own unique experiences that may not be shared by younger generations. These may include wars, genocide, being part of the Stolen Generations, institutionalisation, or unique immigration experiences, with trauma experiences compounding over time. Ageing-friendly, culturally informed services that respond to the potential impact of these experiences and their expression in old age, will result in more positive outcomes. Potential barriers to access should be addressed, such as negative attitudes to ageing, lack of interpreters, lack of cultural awareness and competency, social isolation, poor transportation and financial restrictions. Information that promotes services should highlight improved quality of life, promote healthy ageing, and describe clear pathways to support. Information should be sensitive to literacy issues, including familiarity with technology.

5. Reduce suicide and suicide risk in older people

Suicide continues to be a risk for people as they age. The highest age-specific suicide rate occurs in men aged 85 years and older. Physical illness, health decline, grief, loss of identity, loneliness and social isolation can negatively impact overall wellbeing and be significant contributors to mental illness and suicide. Protective factors such as social connection, feeling in control and satisfaction with life should be actively supported. Promoting help-seeking, along with better recognition of and responses to suicide risk in older people, are key to reducing suicide in all settings. Timely, responsive and appropriate evidence-based support and care, in particular specialist treatment, are also critical.

6. Implement person-centred, trauma-informed recovery-focused approaches, including older person peer worker models

Psychosocial intervention is just as effective in older people as in younger people. Participation in meaningful activities is key to recovery and can include volunteer work, physical activity, mental stimulation and socialisation. Imparting wisdom and knowledge to younger generations can be mutually beneficial and aid recovery and resilience. Peer worker models for older people should be developed, with a focus on the lived experience of mental illness and supporting social connections and meaningful activity. The benefits of social inclusion for older people should be widely promoted.

7. Increase the focus on mental health as being equally important as physical health in care responses for older people

Mental health needs should be given the same priority as physical health needs of older people. Depression, anxiety, substance misuse and other mental illnesses are not a normal part of ageing, but they can become common when we fail to respond appropriately. They need to be addressed in assessment and treatment. Services should also address the wellbeing needs of older people, including loneliness, social isolation and quality of life. Early identification of social isolation in older people and prompt referral to appropriate support services should be a priority, along with a system-level approach to strengthen social inclusion, integrate older people within the community and to improve the overall mental health and wellbeing of the person.

8. Increase the number and capacity of specialist services for older people in line with population ageing

As the population ages, there is and will continue to be an increased demand for contemporary models of specialist mental health and other services for older people. These need to be supported by adequate provision of primary health care, residential aged care and other community based supports. Specialist services should reflect the shift to person-centred, trauma informed practices that actively support older people to define recovery goals and direct their own care. Partnerships between government, community managed (non-government) and private sectors are integral to integrated care and positive outcomes for older people, and need to be pursued as a priority.

9. Increase workforce knowledge and skills

As people live longer with mental health issues and comorbid (co-existing) chronic physical illness, the need for skilled, highly trained professionals and for growth in the care support workforce, becomes paramount. Staff working in hospital, community, residential aged care and primary health care need access to training, backed up by professional standards and competencies, to enhance their understanding, knowledge and skills about older people in general and older people's mental health and suicide risk in particular. Holistic care practices also require understanding of issues that may impact older people's health and wellbeing, such as financial difficulties, social isolation and elder abuse. The resources to secure a stable and competent workforce in the future will require government commitment, along with regulation on skill mix and staff ratios in the residential care sector.

10. Reduce service fragmentation and access barriers through improved governance, care pathways and funding models at federal, state and local levels

Care for older people is fragmented and navigating access to appropriate services is challenging due to current funding arrangements and models of care. Service access pathways need to be easier to travel, with support provided to facilitate access where needed. Collaboration between governments needs to continue to identify and trial alternative models for funding care and services for older people, with a view to enhancing integration and responsiveness to local needs. Governance and funding arrangements need to be transparent, accountable, democratic and consultative, enabling the input of older consumers, carers, service providers and the community in decision making about issues such as resource allocation and service design. Resource allocation should be informed by local clinical and support needs, with bureaucratic hurdles minimised. The processes and outcomes of localised decision making should be benchmarked against evidence-based and expert consensus targets and principles. Promising examples of collaborative care models for older people with mental illness include mental health-residential aged care partnerships implemented through the NSW Ministry of Health's Pathways to Community Living Initiative. Collaboration across the mental health, aged care, primary health care, community managed and disability service systems is critically important.

11. Promote the quality use of medicines for older people

The use of medicines as a treatment for physical or mental illness in older people should follow the four tenets of the quality use of medicines and be efficacious, appropriate, judicious and safe. Older people, and their family or carers where appropriate, should be central to decision-making about their medicine management. Only safe and effective prescription of off-label medicines should occur, recognising the risks of unnecessary or harmful polypharmacy and over-sedation of older people, particularly when used as a form of chemical restraint or to modify challenging behaviours.

The Mental Health Commission of New South Wales calls upon government, private sector providers and the community sector to adopt the vision outlined in this statement, and identify the necessary funding, training and education resources to embed these principles in their practices and programs.

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