

Growing older, staying well

Mental health care for older Australians

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AUSTRALIA

A SANE Report

Growing Older, Staying Well

Mental health care for older Australians

Little is known about the long-term impact of living with mental illness, and yet Australia’s population is rapidly ageing. With this change we will see an increasing number of older adults living with mental illness.

An increase in people ageing with mental illness will create challenges for housing, community support programs, and public mental health services.

People living with mental illness are at an increased risk of developing physical health problems, being isolated, having few supports, and living in unstable housing. These challenges will only be compounded with age.

This report examines the lived experience of older adults with mental illness, their carers, family and friends. It describes some of the major concerns faced by this group and outlines the key areas in need of attention and change.

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Mental illness is experienced by nearly half of the Australian population at some time in life. As the population continues to age, the number of older adults living with mental illness will increase. Mental health care for older Australians is a significant and growing area of concern, requiring action at a national level.

Very little research has looked at the experiences of older Australians living with mental illness. The work that has been done paints a picture of ill health, isolation, inadequate care, and unstable housing.

Growing older, staying well examines the experiences of people aged over 50 living with mental illness. Although older age is usually defined as 65 years and above, the needs of older Australians living with mental illness can be different to the general population. Older people with mental illness are more likely to have multiple physical health conditions, cognitive impairments and few supports, and to experience financial difficulty. These factors contribute to an increased likelihood of needing supported accommodation or experiencing the effects of ageing much sooner. These factors also lead to severely reduced life expectancy; people living with mental illness live on average 25 years less than the general population (Karim, Overshott & Burns 2005).

This report focuses on all mental illnesses common to older adults, including anxiety disorders, mood disorders such as depression and bipolar disorder, psychotic illness such as schizophrenia, and also personality disorders. It is important to distinguish between the terms 'mental illness' and 'dementia'. Both can impair a person's ability to function. However, while some of the symptoms of dementia can present similarly to symptoms of mental illness, they are not related and require different treatments and specialist care.

Above all else, *Growing older, staying well* focuses on the lived experience of older people with mental illness, their carers, family, and friends. By listening to first-hand stories we learnt that many older people living with mental illness do not ruminate on their mental health; instead, they focus on what activities they enjoy, the work they do, their loved ones, and their friends. Mental illness does not define a person. Through listening to the experiences of people, we are able to understand what brings joy and a sense of purpose and meaning in life, and in so doing, develop recommendations for support services that consider the needs of the whole person. This group is no less deserving of stable and safe housing, quality health care and opportunities for participation, and yet they face a variety of barriers that often prevent this.

About the study

The aim of the research was to identify areas of need to support older adults living with mental illness. A literature review identified gaps in the research and helped to develop a survey aimed at consumers and carers. The surveys investigated the experience of ageing with a mental illness and were conducted during February-March 2013 in Victoria. 111 responses were received. Most respondents were female (73%) and aged predominantly between 50 and 64 (74%). The diagnoses reported were most frequently depression (45%) followed by schizophrenia (28%), bipolar disorder (23%), anxiety disorders (3%) and personality disorders (1%). In addition to the surveys, 26 interviews were conducted with consumers and service providers. Results have been used to identify barriers to effective care and to make recommendations for improvements.

Staying Well

People who live with mental illness and get out of bed are my heroes. The energy and determination to manage a mental illness is enormous.

The concept of wellness can be difficult to describe. In one interpretation of the term, wellness is not defined as the absence of illness, but the presence and active pursuit of purpose, participation, relationships and happiness (Swarbrick, 2013). It is a state of being that we all strive to achieve, but some people face barriers that can make the journey to wellness particularly challenging.

The people we spoke to who live with mental illness are a highly resilient group. They spoke of barriers to wellness such as poor physical health and access to quality health care, but they also talked about ways in which they overcome these challenges to achieve wellness.

I'm pretty tenacious, and I'm well put together otherwise I don't think I would have survived. I am tough and resilient. I fought my way through this. I had to dig deep. Also, not smoking or drinking, not taking drugs, eating well, and exercising have helped.

When asked to list what would help to improve their quality of life, physical health and more social contact were the most prominent responses. A reduction in the stigma surrounding ageing and mental illness was also cited as an important issue. Respondents wanted to be connected in the community and engage in meaningful activity such as employment or a volunteer position.

Understanding how older people living with mental illness achieve and maintain wellness goes a long way in developing appropriate intervention strategies and models of care. The majority of respondents to the surveys had lived with mental illness for many years, with 44% having been diagnosed 21 to 50 years prior. Some of the challenges of living with mental illness are overcome with time and experience, and many of the people in this group have great insight into managing their condition.

Peer support and speakers programs are a good way of sharing information through experience and play a large role in reducing the stigma surrounding mental illness. Yet many of the programs based on a peer support model are focused on adolescent and adult mental health. Drawing on the experience of older people living with mental illness will help to educate and support not only their peers, but also younger adults, adolescents, and children.

Recommendation

Consult with older adults when seeking to understand the experience of living with mental illness.

ACTION The National Report Card on Mental Health and Suicide Prevention has recommended a regular national survey of people's experiences with mental illness. This survey should strive to include older adults. Furthermore, older adults should be actively recruited as peer educators for training workshops and support programs.

Mind and Body

I look at my mad comrades and I think this just isn't right. Their physical health is down the tube; it is an absolute medical disgrace. It seems wrong that sanity comes at the price of your physical health. And we have to make that choice, we are forced to make this choice.

Taking medications over many years that may have negative side-effects on physical health, coupled with the advancing effects of age, puts older people living with mental illness at a disadvantage in managing physical health as they age.

60% of respondents found that the medication they take for mental illness had an unwanted effect on their physical health.

Complicating this issue is the tendency for the presence of one diagnosis to interfere with the detection or diagnosis of another: the 'overshadowing effect' (Jones, Howard & Thornicroft 2008).

My GP has overlooked some physical health problems over the years because of focusing too much on my mental health. Fortunately these issues have been picked up by another practitioner I see occasionally.

Recognition and treatment of physical health conditions as well as mental illness is crucial because the presence of one may adversely affect the other. Older adults living with mental illness are less likely to receive the physical and mental health treatment they need.

67% of respondents live with at least one physical health condition.

Over half of the respondents live with hypertension and diabetes.

Respondents most often see a GP for both their physical and mental health needs. Where a GP was the main person monitoring mental health, people often reported feeling that the doctor did not fully understand the effects of mental illness.

I think GPs are usually badly informed about mental illness, they seem to be lacking in mental health literacy. I sometimes think that they just don't want to deal with mental health stuff because it is beyond their skill set.

Evidence suggests that a combination of medications and psychotherapy can lead to positive outcomes in the treatment of mental illness in older people (Bartels et al, 2002). However, they are most likely to be treated with medication alone.

91% of respondents are prescribed medications for the treatment of mental illness.

50% of respondents are receiving psychotherapy for the treatment of mental illness.

Respondents find it difficult to access adequate care from health professionals. This is especially the case in supported accommodation facilities where a GP will often support many residents, and spend only a matter of minutes with each.

Continued overleaf

Mind and Body

Continued

My physical health needs are not met by my GP because he only stays with me for five minutes. There are a lot of things I would like to talk to him about, but it's not enough time.

60% of respondents consider decline in physical health as their greatest concern for the future.

Respondents worry that a loss of physical health will affect their independence, and that they will no longer be able to do the activities they enjoy. For some, issues with physical health and mobility have already caused them to stop activities. This reduction in activity and involvement can lead to grief and loss, and may increase the likelihood of developing depression in older age.

When I was well enough I used to do physical things like playing golf or going for a walk. But now that I can't do those things I sit here and cry.

Mind and body are inextricably linked. Without one, we are vulnerable to the ill health of the other. For older people living with mental illness, GPs are usually the primary, and at times only, health professional providing care. GPs need to be encouraged and educated, therefore, to provide holistic care to this group.

Recommendation

Encourage GPs and other primary health professionals to seek additional training and education in the treatment of co-existing physical and mental health problems.

ACTION Provision of widely available training modules delivered to primary health professionals to help increase knowledge around the experience of mental illness in older adults.

Having a Home

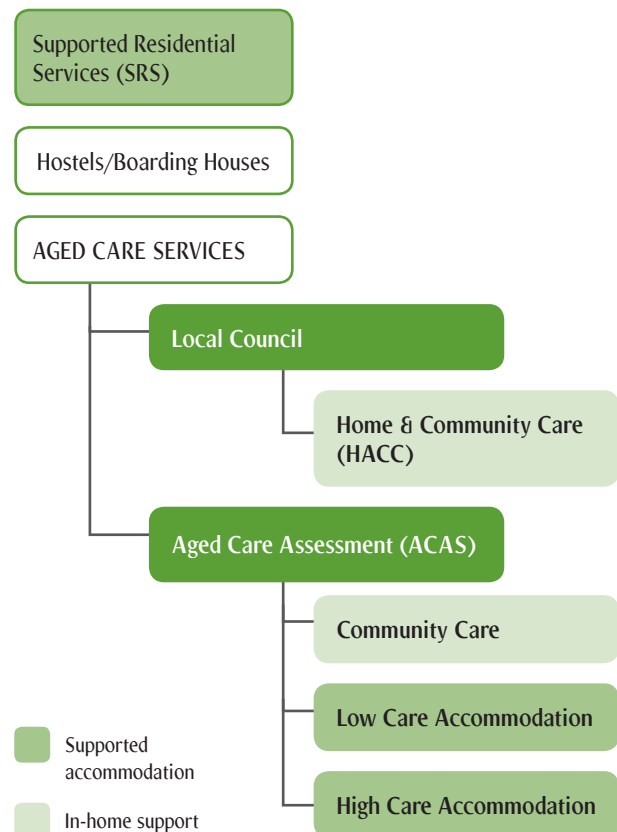
I worry about having to move out of this beautiful little unit into somewhere I don't want to be.

According to the Australian Bureau of Statistics (ABS, 2009), people living with mental illness find it harder to find and keep their own home compared to the general population. For people who are entering older age, the situation may become further complicated for a number of reasons:

- ▶ The death or incapacity of an ageing caregiver may result in an immediate need for housing support.
- ▶ Lack of employment in younger years and living on a pension means that many older people living with mental illness often do not own their own home or have adequate superannuation in order to secure appropriate housing.
- ▶ This group may experience the effects of ageing sooner, and therefore require supported accommodation at a younger age than the general population.
- ▶ The complex care needs of older people living with mental illness are often not recognised in funding supplements for aged care services. This may result in a shortage of resources including, staff, transport, and ongoing training and education.

Those who need additional help with housing and daily supports can access support through a number of channels. The aged care system typically provides supported accommodation and in-home help. These services are partially supported through government funding. A person must have an assessment through the Aged Care Assessment Service (ACAS) in order to access these services. Alternatively, a person may access limited in-home assistance (for example, with showering and shopping) through a Home And Community Care (HACC) program, for which an aged care assessment is not required.

Continued overleaf



Having a Home

Continued

For those who are no longer able to live unsupported, who do not qualify for an aged care assessment, and who may have few supports, pension-level Supported Residential Services (SRS) provide accommodation for a percentage of the pension. Alternatively, boarding houses and hostels provide a room with utilities. Historically, SRS, hostels and boarding houses have provided accommodation to a large number of people living with mental illness after the closure of long-term institutionalised care. Due to the lack of government support these services function on very limited resources. They are not considered high-care facilities, and yet they often provide care to people with complex physical and mental health needs.

It seems as though the money that should have followed people out of institutions into the community never really happened, and therefore SRS have become something of a dumping ground for people with complex mental health issues. Clinician

Older people living with mental illness may experience the effects of ageing much sooner, and therefore require access to aged care services for daily support needs. However, service providers find that there is a reluctance to provide aged care assessment to those under the age of 65. Unfortunately this can mean that clients are discharged into unstable housing. This can make it hard to reach people, and also worsen the person's mental health.

The Aged Care Assessment Teams are often reluctant to see a person under 65, and therefore we often see clients who have to be discharged into an SRS. Clinician

While many health professionals are willing to provide their services on an outreach basis, many do not, and this creates problems for access to quality health care for residents.

All of the respondents living within supported accommodation have access to a GP, yet only 38% have access to a mental health professional.

Quality of care in hostels, boarding houses, and SRS is often dependent on factors such as skilled management practices and personal care workers. However, there is currently no requirement for those entering personal care to have mental health training.

Staff working in mainstream aged care report a variety of barriers to recognising mental health issues in their clients including limited time to devote to the recognition of psychological distress, limited training, and poor working conditions (McCabe, Davison, Mellor & George, 2009).

The treatment and care of physical and mental health is complex. It requires experience, education and understanding. The complex care needs of older people living with mental illness must be recognised in policy reform and program funding in order to encourage mental health education and training for those working with older adults living with mental illness.

Recommendation

Mandatory mental health training for staff working in the aged care and community support sectors.

ACTION Training workshops delivered as professional development for staff working within the aged care, and community support sectors. Workshops would aim to raise awareness about mental illness in older Australians including disorders such as schizophrenia and bipolar disorder.

Social Isolation

SOCIAL ISOLATION

The absence of relationships with family and friends on an individual level and with society on a broader level. (Step toe, Shankar, Demakakos & Wardle, 2012).

Social isolation is a problem that can affect people at any age, and while it is not an inevitable part of old age, it is more likely to affect older adults living with mental illness because of grief, ill health, and financial instability.

31% of respondents consider social isolation to be a major concern for the future. For those respondents who live in a private home isolation was cited as the most negative aspect of where they live, and carers identify social visits as the most effective intervention in prolonging the time a person can live independently.

Sometimes I feel quite scared about getting older. I am on my own and already isolated and lonely. I can only imagine that this will get worse.

Older adults living with mental illness may be more vulnerable to social isolation due to a lack of opportunities for participation in the community. Furthermore, this group may experience health conditions and issues with mobility that prevent participation. Active outreach models are a crucial part of any community-based intervention to prevent social isolation.

While the experience of social isolation can have a profound effect on the individual, service providers find that clients who have experienced social isolation can be distrustful of health services.

It is all about social inclusion. Making sure that clients are linked in to the community and confident enough to access services. Many clients can be distrustful of health services. The social isolation is a major issue.
Program Manager, NGO

In order to address the issue of isolation within supported accommodation, many activities and programs have been developed, but these are often generic and may have little to do with the personal interests and enjoyment of the individual. Person-centered care is the cornerstone of policy reform in the area of aged care, and it is crucial that this approach be implemented in all aspects of the care environment including in social activities and programs.

DID YOU KNOW?

The experience of social isolation has a negative effect on physical and mental health. So much so, that researchers have compared the health impact of social isolation with that of being a smoker (House, 2001).

Researchers increasingly understand isolation as a major contributing factor to ill health, and early death. It should therefore be a focus of all discussions to improve the care and support provided to older adults living with mental illness.

Recommendation

Address social isolation in older adults living with mental illness as a central tenet of any policy reform and advocacy work in this area.

ACTION Recruit older adults as peer educators for training workshops and support programs. This would encourage participation and community involvement therefore helping to reduce social isolation.

Loss and Grief

As I've grown older, I've had more time to think about the things that make me sad and I wish I could change.

The experience of loss and grief is a major issue affecting this group. Older adults living with mental illness experience loss in relation to issues such as independence, status, death of loved ones, and financial stability. The stress associated with many of these losses may complicate the management of mental illness in older people and contribute to depression in later life.

72% of respondents report that the symptoms of their mental illness changed as they became older.

48% of these experienced more depressed feelings; most attribute this to loss and grief.

It is crucial that health professionals, care workers, and the wider community acknowledge the burden of loss and grief in later life. One of the most dangerous misconceptions about the experience of ageing is that people will become depressed as they grow older. Depression is not a normal part of ageing, and yet this assumption can prevent health professionals and care workers from identifying older people who are not coping.

The risk of suicide is substantial in later life, with one of the highest rates being among men 75 years and over (ABS, 2012). Sadly, the majority of older adults who have died by suicide had seen their GP in the month prior (Segal et al, 2011). Acknowledging the impact of loss and grief in older adults living with mental illness and providing psychotherapy may assist in reducing depression in this group.

DID YOU KNOW?

Australia has one of the highest levels of pet ownership in the world, with 59% of households having a cat or dog.

A number of studies have shown the physical and mental health benefits of pet ownership. Pet owners visit their GP less often for day-to-day health issues, and have lower risk for heart disease than the general population. Conversely, the loss of a pet can have a devastating impact on a person. For older adults moving into supported accommodation the loss of a beloved pet can lead to constant and deep grief. Some supported accommodation facilities encourage pets, but this is generally the exception not the rule, and therefore is an important discussion to have when deciding on long-term accommodation options. In some areas, programs have introduced animals into care facilities, such as the *DOGS Victoria Therapy Group* in Melbourne.

Stigma

STIGMA

Uninformed and negative attitudes held by many in the general community towards marginalised people.

I know people that can't get a job to save themselves, and that is because of age. It's not fair. And ageism is still out there and it can be aggravated by your illness.

The impact of stigma further complicates the challenges encountered by older people living with mental illness. The dual stigma of older age and mental illness is so pervasive that it can affect all aspects of a person's life.

At an individual level, stigma may result in hesitation when accessing health services, social withdrawal, and poor self-worth (SANE Australia, 2008). At a systems level, stigma can result in a lack of available services and funding, hesitation when accepting a referral, poor media portrayal of ageing and mental illness, inadequate treatment options, and a lack of support for friends and family.

There is not enough funding to do everything we need to do. Stigma is a huge issue for this group, and it prevents people from being given adequate care. This group is most often likely to need help, but less likely to be provided with this help. Clinician

For older Australians living with mental illness, the experience of stigma can lead to fear and anxiety accessing services and supports.

I see things like residents telling me that their cat has started to talk to them, but they swear me to secrecy because they are afraid if they tell someone they will be hospitalised against their will, and the problem is, I can't promise that they won't be. Mental health worker

The service providers interviewed have found that there is a reluctance to work with this group, and as a result it can be challenging for referrals to be picked up. In addition to this, it is difficult to attract volunteers and staff to aged mental health.

Stigma surrounding mental illness is the biggest challenge because service providers are reluctant to work with this group and many programs have problems securing good volunteers. Program Manager, NGO

Negative perceptions of mental illness in the mainstream aged population can also prevent people from accessing services.

I am almost of an age now where I could join a seniors club, and yet my generation who are not living with mental illness are more stigmatising than most other people because of all the old conceptions of mental illness.

The impact of stigma is very serious. It can prevent people from accessing health services and lead to self-stigma. Public education is an integral part of reducing stigma. Highlighting the issues faced by older people should be an important part of awareness campaigns addressing the stigma surrounding mental illness.

Recommendation

Stronger lobbying and advocacy giving the needs of older people living with mental illness more prominence in aged care and mental health.

ACTION Targeted awareness campaign about the issues experienced by older adults living with mental illness and a stigma reduction program aimed at the aged care sector.

What lies ahead?

The fear of losing your home, the fear of being isolated and the fear of the uncertain future is enough to send you crazy.

Entering retirement age can be both an exciting and challenging time for all older Australians. However, transition also requires planning. For a person ageing with mental illness, it is especially important to plan for the future as they may have multiple supports that will need to continue in order to stay mentally healthy.

Unfortunately, the aged care and mental health systems are notoriously difficult to navigate. In many cases access to supports may require long periods on waiting lists and collaboration between multiple services. In the event of the death or incapacity of a carer, multiple areas of support may need to be coordinated on short notice.

67% of respondents have not spoken with their carer or support person about a plan for their future care – yet the majority are cared for by an elderly parent or sibling.

Older people may not be talking about plans for their future care, but they do cite a number of issues that are a concern for the future.

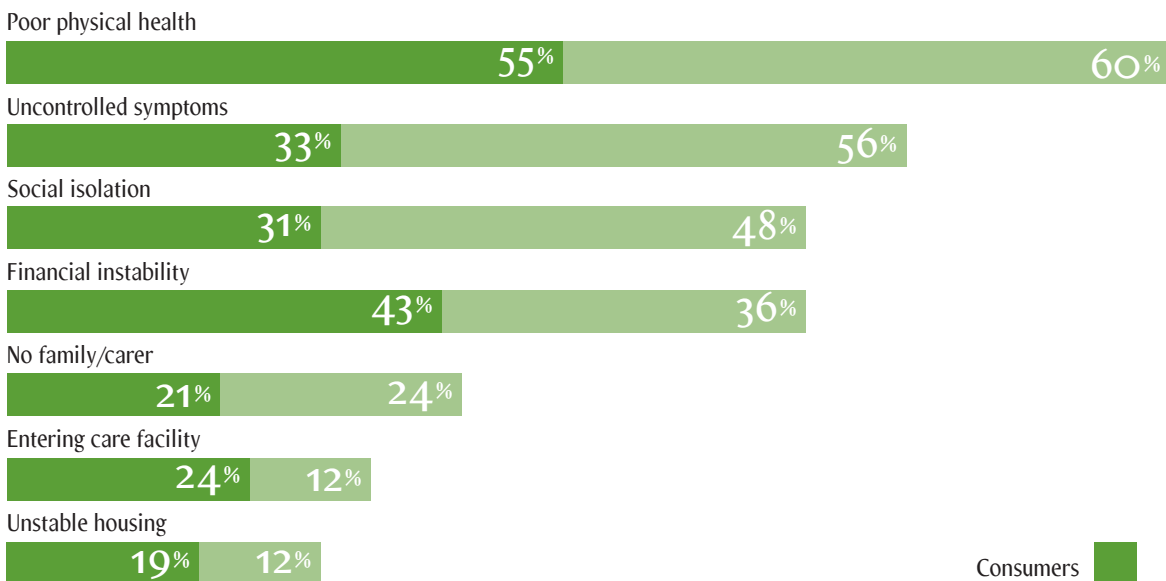
Planning for the future is an important part of all our lives, but for a person living with severe mental illness the need to do so is crucial. If this process is left too late, the challenge of coordinating multiple services and securing adequate housing can have a negative impact on mental health. Furthermore, not planning for this time can put undue pressure on caregivers. We need to help educate older adults, their family and friends about the importance of forward planning.

Recommendation

Provide clear and easily accessible information for older adults, their families, friends and staff about mental illness in older age.

ACTION Develop information resources in order to educate older adults, family, friends, and carers about the signs and symptoms of mental illness as we age, what to do if you are concerned, and how to plan for future care needs.

Greatest concerns for future



Summary and Recommendations

As our population continues to age, the experiences of older Australians become increasingly important. For older Australians living with mental illness, the experience of ageing can bring many challenges, yet these challenges are poorly understood in our communities.

Growing older, staying well has outlined some of the challenges, but this is, of course, not the whole picture. The needs of older adults living with mental illness vary and will differ depending on age, history of care, financial supports, and cultural backgrounds. The purpose of this report is to raise awareness about some of these issues and to encourage the community to start asking questions: What can we learn from older adults? What is their story? And how can we help?

There have been many changes to aged care policy, but there is still a lack of attention to mental illness in the elderly. If we are to work towards an inclusive society then we must consider all its citizens. Ageing Australians living with mental illness should be valued members of our communities; they bring a humbled and humbling wisdom and a wealth of experience. As a nation which aspires to lead the world in the provision of mental health services, we will greatly benefit if we take the time to listen to, and support, this group.

Sector Perspective

The service providers interviewed said that additional attention should be focused on the following major issues:

- ➊ Better communication and collaboration between public mental health, aged care and non-government organisations (NGOs).
- ➋ Mental health training and education for all staff working in the aged care and community support sector.
- ➌ Stigma reduction campaign targeted at the aged care sector and community support services around the issue of mental illness in older adults.
- ➍ Program funding that considers the complex care needs of this group.

Recommendations

- 1 Stronger lobbying and advocacy giving the needs of older people living with mental illness more prominence in aged care and mental health.

ACTION

Targeted awareness campaign of public education about the issues experienced by older adults living with mental illness, and a stigma reduction program aimed at the aged care sector.

- 2 Address social isolation in older adults living with mental illness as a central tenet of any policy reform and advocacy work in this area.

ACTION

Peer education and support programs are a great way to learn through experience; however these programs have traditionally been more focused on younger adults. Developing peer education and support programs aimed at older adults will encourage participation therefore helping to reduce isolation.

- 3 Consult with older adults when seeking to understand the experience of living with mental illness.

ACTION

The National Report Card on Mental Health and Suicide Prevention has recommended a regular national survey of people's experiences with mental illness. This survey should strive to include older adults. Furthermore, older adults should be actively recruited as peer educators for training workshops and support programs.

- 4 Mandatory mental health training for staff working in the aged care and community support sectors.

ACTION

Training workshops delivered as professional development for staff working within the aged care, and community support sectors. Workshops would aim to raise awareness about mental illness in older Australians including disorders such as schizophrenia and bipolar disorder.

- 5 Provide clear and easily-accessible information for older adults, their families, friends and staff about mental illness in older age.

ACTION

Develop information resources in order to educate older adults, family, friends and carers about the signs and symptoms of mental illness as we age, what to do if you are concerned, and how to plan for future care needs.

- 6 Encourage GPs and other primary health professionals to seek additional training and education in the treatment of coexisting physical and mental health problems.

ACTION

Provision of widely available training modules delivered to primary health professionals to help increase knowledge around the experience of mental illness in older adults.

- 7 More research focused on mental illness in older adults.

ACTION

There is no shortage of research into the experiences of older adults, but much of this is focused on dementia and physical health problems; there is still a lack of attention to mental illness in the elderly. Additional research in this area will help to encourage discussion around the issues faced by this group.

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