

# **MENTAL HEALTH AND OLDER PEOPLE**

*World Mental Health Day, October 10 2013*

*World Federation for Mental Health*





*World Mental Health Day  
October 10 2013*



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# Foreword

World Mental Health Day was initiated by World Federation for Mental Health (WFMH) in 1992 to highlight the importance of mental health. The WFMH Board of Directors of WFMH has chosen “Mental Health and Older Adults” as the theme for World Mental Health Day on 10th October 2013.

The theme highlights the lengthening span of the life course which in many developed countries encompasses more years at work, more years of an active lifestyle in retirement, and a growing cohort of “oldest old” people in their 80s and 90s. This is creating a new concept of “old age.” In lower-income countries citizens often have shorter lifespans, and receive limited help as they age. The promotion of good mental health is an important part of the World Mental Health Day theme, as is attention to the mental health problems that older citizens may experience.

Many adults enjoy vigorous activity as they age and remain in the workforce longer. Once retired they may contribute to society as volunteers and often provide family support such as caring for grandchildren or for an infirm spouse or relative. Social connections have been recognized as a positive factor in promoting the wellbeing of older adults, and strategies to strengthen a network of such connections are very valuable.

Some key facts:

- The proportion of the world’s people reaching old age is growing dramatically as a consequence of success in improving health care and living standards.
- According to the World Health Organization the proportion of the world population over 60 years will double between 2000 and 2050, from around 11% to 22%.
- Within the cohort of older adults, more people are living to be over 80 and 90.
- Women predominate among those reaching extreme old age, as they have longer life spans on average.

- Older people often have several health problems at once; long-term conditions such as heart conditions, cancer and diabetes are known to place people at risk for mental disorders, and a number of them will experience depression and anxiety.
- Substance abuse involving alcohol and drugs is an issue that is often ignored.
- Dementia is a rising problem as more people live into extreme old age.

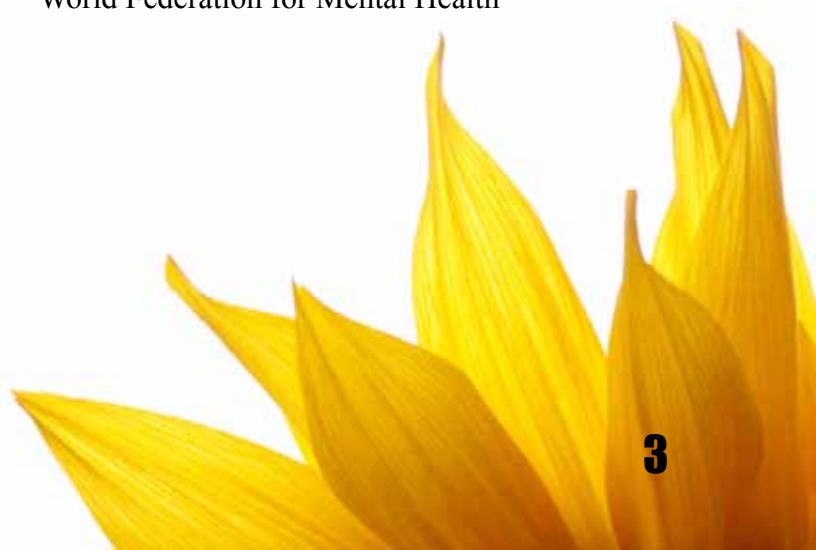
World Mental Health Day 2013 aims to encourage governments and organizations around the world, in countries at all income levels, to look at the mental health issues experienced by older people in their communities and to consider their needs for support and services. Improvements in provisions for care require careful planning, advocacy, and the involvement of concerned individuals.

I would like to express my appreciation for all those who have contributed to WFMH’s promotional material for World Mental Health Day 2013 and, as President of the World Federation for Mental Health; I am making a personal appeal to you to support this year’s theme of Mental Health and Older Adults in whatever way you can.

Let the elderly have a voice, a place and dignity.



Prof. George Christodoulou  
President  
World Federation for Mental Health



# *Mental Health of Older Adults, Addressing* **A GROWING CONCERN**

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## **Background**

The world population has never been as mature as now. Currently, the number of people aged 60 and over is more than 800 million. Projections indicate that this figure will increase to over two billion in 2050. People aged 60 can now expect to survive an additional 18.5 to 21.6 years (1). Soon the world will have a higher number of older adults than children. Contrary to common sense perceptions, the majority of older people live in low- and middle-income countries, and some of the fastest rates of ageing are occurring in these areas (2, 3).

The United Nations uses the benchmark of 60 years of age or above to refer to older people (UNFPA, 2012). However, in many high-income countries, the age of 65 is used as a reference point for older persons as this is often the age at which persons become eligible for old-age social security benefits (1, 2). This higher age category is less appropriate to the situation in developing countries including Africa where life expectancy is often lower than that in high-income countries (4).

Older adults face special health challenges. Many of the very old lose their ability to live independently because of limited mobility, frailty or other physical or mental health problems and require some form of long-term care. Early on, in the beginning of the millennium, it became clear in the USA that about 20% of adults aged 55 and over suffer from a mental disorder (5). Subsequently, global statistics showed this to be an almost universal problem (6). Mental health problems of older adults are under-identified by health care professionals and older people themselves, and older people are often reluctant to seek help.

## **Underlying factors of mental health problems in older adults**

A multitude of social, demographic, psychological, and biological factors contribute to a person's mental health status. Almost all these factors are particularly pertinent amongst older adults.

Factors such as poverty, social isolation, loss of independence, loneliness and losses of different kinds, can affect mental health and general health. Older adults are more likely to experience events such as bereavements or physical disability that affect emotional well-being and can result in poorer mental health. They may also be exposed to maltreatment at home and in care institutions (7). On the other hand, social support and family interactions can boost the dignity of older adults, and are likely to have a protective role in the mental health outcomes of this population.

There are more older women worldwide than older men. This difference increases with advancing age and has been called "feminization of ageing". Older men and women have different health and morbidity patterns and women generally have lower income but better family support networks (1). On the other hand both depression and Alzheimer's disease are more prevalent among women (8).

Intergenerational solidarity is declining, especially in high-income countries. In some low- and middle-income countries a grandparent is increasingly more likely to be living with a grandchild. These so called "Skipped Generation" living arrangements are becoming more common because of economic migration, and in some societies as a consequence of HIV/AIDS related deaths. The impact of this on the

perceived social stress amongst older people needs further research (1).

The drastic demographic change brings about new challenges but also potential opportunities. The socioeconomic impacts, paired with health consequences, are new concerns for the world. This creates a paradoxical situation. Changes in the social role of the elderly have an impact on their wellbeing. In a considerable proportion of countries, older adults are now in better health as compared with the past. Older adults are increasingly “expected” to be more productive and are even being asked to contribute more to their family and/or community. Conventional attitudes toward the elderly have typically been considerate of their dignity, with a few exceptions in some cultures. However, the current expected role of an elderly person seems to have changed from the role of “sage advisor” as it used to be in most parts of the world. Retirement age is increasing in many high-income countries. Older people are expected and are able to make important contributions to society as family members, volunteers and as active participants in the workforce, provided they stay fit enough for carrying out such roles. Nevertheless, improving productivity and asking older adults to provide support to communities and families must be complemented by additional support to them from society.

An important risk factor to the health and mental health of older adults, and an important human rights issue, is elder maltreatment. WHO defines elder maltreatment as “a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust that causes harm or distress to an older person”. This type of abuse includes; physical, sexual, psychological, emotional, financial and material abuse; abandonment; neglect; and serious loss of dignity and self-respect. In high-income countries where data exists, around 4-6% of older persons have experienced some form of maltreatment at home. The frequency should be even higher, as many older adults are too scared or are unable to report maltreatment. Though data on the extent of the problem in institutions including hospitals, nursing homes and other

long-term care facilities are scarce, it so far indicates much higher rates as compared with maltreatment at home. Elder maltreatment can lead not only to physical injuries but also to serious, sometimes long-lasting psychological consequences, including depression and anxiety (9).

### **Promotion of mental health within a healthy ageing framework**

Mental health of older adults can be improved through promoting active and healthy ageing. To promote healthy ageing, the socio-economic determinants and inequalities in health need to be dealt with and additional gender and minority disparities need to be tackled. Stereotypes against active ageing are called “ageism” and need to be reversed. Ageist attitudes consider older adults as frail, “past their sell-by date”, unable to work, physically weak, mentally slow, disabled or helpless. Ageism serves as a social divider between young and old and prevents participation in society. Age discrimination has a negative impact on the wellbeing of the elderly (10). Ageing is a gradual process and there is much we can do to promote good mental health and well-being in later life. Participation in meaningful activities, strong personal relationships and good physical health are key factors. Poverty is a risk factor for the mental ill-health of older adults and needs to be taken into consideration (11). Addressing elder maltreatment is a critically important approach for the promotion of mental health among the elderly. Primary health and community care and social service sectors need to be sensitized and supported to deal with elderly abuse. Deinstitutionalization and close monitoring of the remaining institutions are important additional strategies towards better service provision for the ageing population.

Promoting healthy life styles among the general population, starting from an earlier age with strategies such as increasing physical and mental activity, avoiding smoking, preventing harmful use of alcohol and providing early identification and treatment of non-communicable diseases (NCDs) can contribute to better mental health among older adults.

Involving civil society, non-governmental and non-

profit organizations, and public-private partnerships could facilitate the implementation of health promotion strategies for older adults.

### Physical health problems in older adults

Even in resource-poor countries, more older people die of NCDs such as heart disease, cancer and diabetes than from infectious and parasitic diseases. In addition, older people often have several concurrent health problems (8). Risk factors for degenerative brain disease such as high blood pressure, diabetes and high cholesterol levels are increasing among older adults (12).

Mental health has a big impact on physical health. For example, coexisting depression in people with diabetes is associated with decreased adherence to treatment, poor metabolic control, higher complication rates, decreased quality of life, increased healthcare use and cost, increased disability and lost productivity, and increased risk of death (13). Conversely, people with medical conditions such as heart disease, diabetes, asthma and arthritis have higher rates of depression than those who are medically well (14).

## Mental disorders in older adults

### Dementia

Dementia is a syndrome involving deterioration in memory, thinking, behaviour and the ability to perform everyday activities such as dressing, eating, personal hygiene and toilet activities (15). It generally affects older people, although it is not a normal part of ageing. A report by WHO and the Alzheimer Disease Association International (ADI) in 2012 suggests a crude estimated prevalence of 4.7% among people 60 years and over. This indicates that 35.6 million people are living with dementia (12). The total number of people with dementia is projected to almost double every 20 years. That is, to 65.7 million by 2030 and up to 115.4 million by 2050 (12). Much of this increase is attributable to the rising numbers of people with dementia living in low- and middle-income countries ( Figure 1). There are significant social and economic implications in terms of direct medical costs, direct social costs and the costs of informal care. The total cost as a proportion of GDP varied from 0.24% in low-income countries to 1.24% in high-income countries (12).

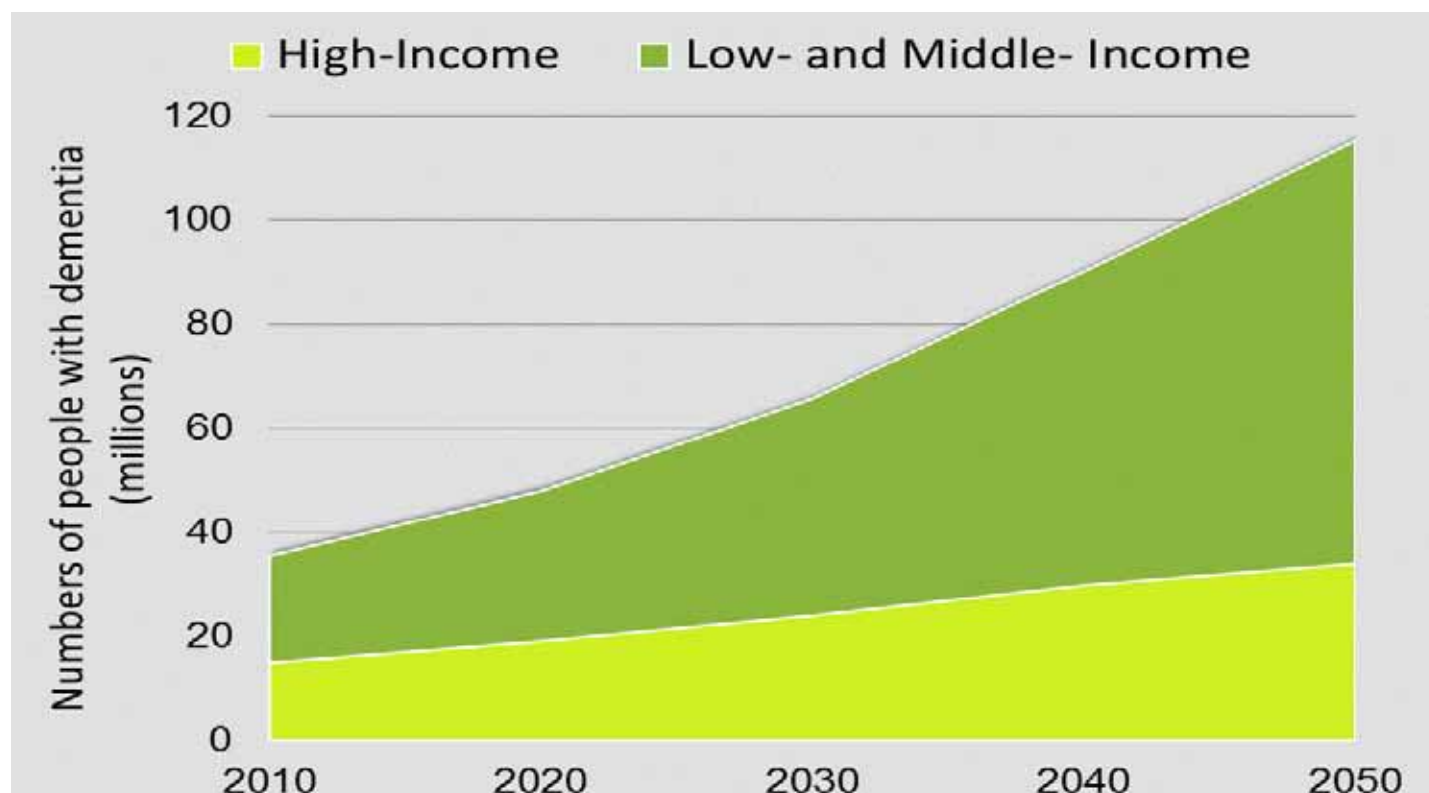


Figure 1: Increase in numbers of people with dementia, by income group of countries

Though no cure is available, much can be done for people with dementia and their caregivers. A range of pharmacological and several non-pharmacological interventions are available and can be delivered by even non-specialized health providers (15 & 16).

### ***Depression***

Depression is common in old age. According to the Institute of Health Metrics and Evaluation (IHME) 2010 data, the Disability Adjusted Life Years (DALYs) for depression (major depressive disorder plus dysthymia) over 60 is 9.17 million years or 1.6% of total DALYs in this age group (17).

Symptoms of older adults' depression differ only in part from early life depression. They may however have more somatic presentation (18). This, together with high comorbidity with other physical conditions, can create a challenge for diagnosis. Once trained properly, non-specialized health care providers can identify and treat depression among older adults. Effective psychological and pharmacological treatments exist; however, great care needs to be taken when prescribing antidepressants to this age group. Health care providers should prescribe reduced initial doses of antidepressants and finish with lower final doses (15, 19 & 20). If severe, depression may lead to suicide. Comorbidity with alcohol use disorders increases the likelihood (21).

### ***Other mental disorders***

Though substance abuse problems are thought of as young people's problems, they should not be neglected in older adults. Substance abuse problems among the elderly are often overlooked or misdiagnosed. In Europe, the number of older adults with such problems will double from 2001 to 2020 (22). According to IHME 2010 data, the absolute DALYs for alcohol disorders for people over 60 is about 1.5 million years. This constitutes about 0.3% of total DALYs for this age group (17). The corresponding figures for other substance use disorders are 338,000 years and 0.1%. Availability of maintenance treatments and better health care have contributed to an increased number of older adults who survive early onset drug use. Stressful life events such as retirement, marital breakdown or bereavement, social

isolation, financial problems, mental disorders and some chronic physical conditions are main contributing factors to substance abuse. Physiological changes associated with ageing and increased use of other medicines, especially sedatives, may make drinking in lower doses more harmful for older adults through inducing more liver damage and causing more accidents and injuries (22).

Prescribing for older adults is common. Some prescribed medicines such as benzodiazepines and opioids have a potential for abuse or dependence and this may occur within or outside a medical context.

Treatment of substance use disorders in older adults is at least as effective as in younger adults. Treatment of health conditions due to substance use, especially management of withdrawal states or substance-induced psychoses, should be delivered in a supportive and, if necessary, medical environment, with proper consideration given to interactions between psychoactive substances and prescribed medicines as well as to other health complications.

Mental disorders are more common among people with intellectual disabilities (ID). Also the number of people with intellectual disabilities who reach a sufficiently advanced age to develop dementia is increasing. The already challenged level of cognitive functioning is more vulnerable to dementia. Many high-income countries have strengthened their research activities and services for this group of older adults. Overall, this is a new area of work and so far the preference is for involving primary and community care and to prevent institutionalization (23).

### ***Mental health of the caregivers***

Older adults with dementia and depression commonly receive support from spouses, other family members or friends. Caregivers commonly go through high levels of burden, stress, and depression (24). Providing psychosocial care to them should be included in the intervention packages for mental disorders of older adults. Psychoeducational interventions such as training for caregivers that involves their active participation (e.g. role playing of behavioural problem management) are effective interven-



tions for caregivers of people with dementia. Carer psychological strain needs to be addressed with support, counselling, and/or cognitive behavioural interventions. Depression is common among caregivers and should be managed properly (15).

### **WHO's response to the need**

WHO's programmes for active and healthy ageing have provided a global framework for action at the country level (25). WHO recognizes dementia as a public health priority and supports governments in strengthening and promoting mental health in older adults, particularly in low- and middle-income countries. WHO's flagship programme, the mental health Gap Action Programme (mhGAP) included dementia as one of its main priority conditions. The mhGAP-IG (intervention guide) includes evidence-based interventions to be delivered by non-specialized health providers in low-income settings for all priority conditions including dementia, depression, and alcohol and substance abuse (15).

The WHO/Alzheimer's Disease International report *Dementia: a public health priority*, published in 2012, aims to provide information and raise awareness about dementia. It also aims to strengthen public and private efforts to improve care and support for people with dementia and for their caregivers (26).

The latest World Health Assembly of 24 May 2013 considered older people to be a vulnerable group with a high risk of experiencing mental health problems in its report "Comprehensive mental health action plan 2013–2020". Among its requests to the Director General of WHO, the Assembly included long-term care for older people (27).

### **Conclusion**

The number of older adults is growing fast all over the world. The socioeconomic impact of such demographic changes is adding to overall mental health consequences.

WHO is supporting governments to narrow down the service gap for mental health, particularly in resource-poor settings.

Though we still need more research on the biological, psychological and social aspects of older adults' mental health, we already know enough to make a difference.

We must improve general wellbeing through a life course approach and by promoting healthy life styles. We need to identify and treat mental disorders among this age group as early as possible. It is important to improve the social capital and involve communities and families in supporting the older adults. We need to support and engage non-profit organizations, NGOs and the peer groups of older adults. We should also establish public-private partnerships to fill the service gap.

Awareness on what has proved to be effective so far is extremely important. We need to fight against the maltreatment of older adults and abandon "ageist" attitudes by inviting the full participation of older adults into everyday life.

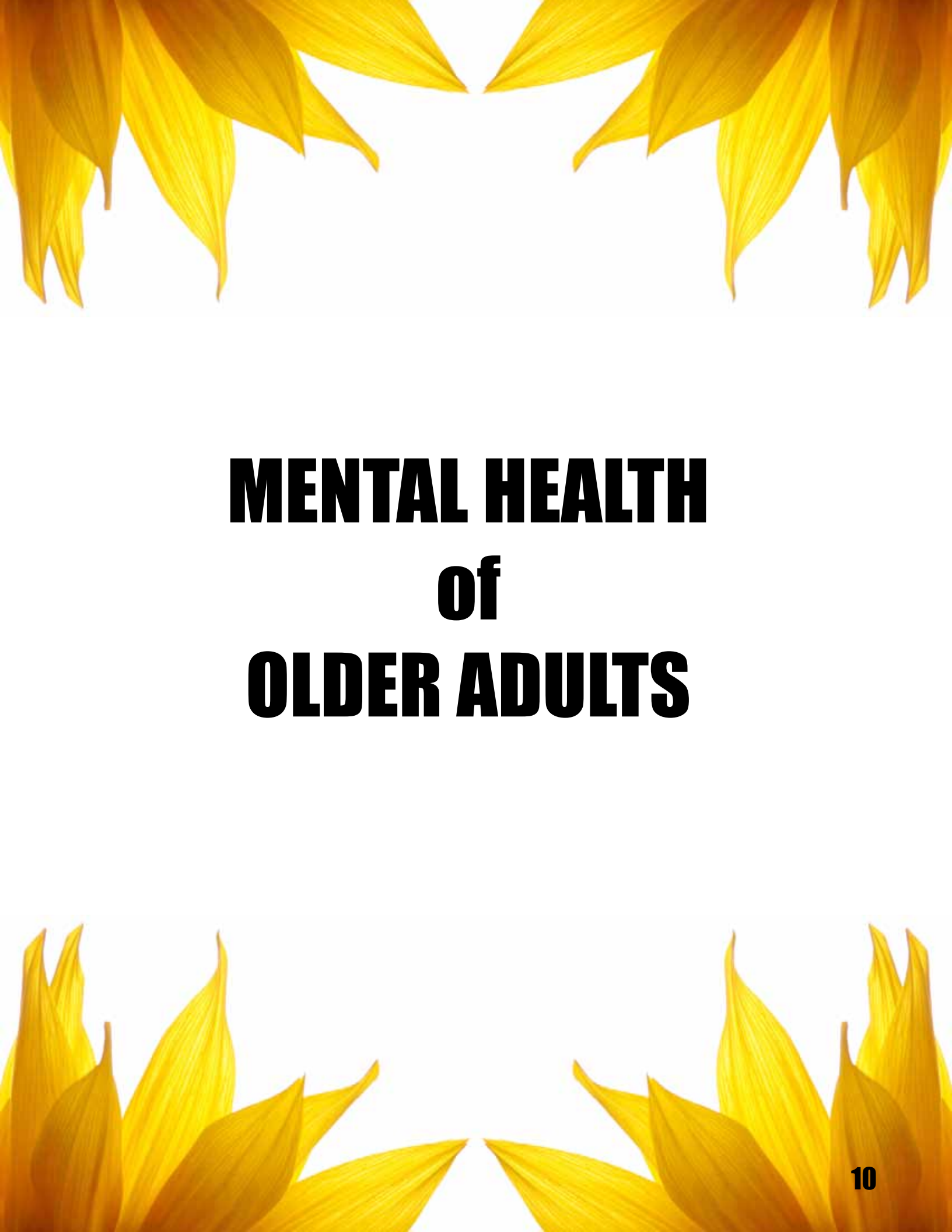
Many older adults still follow a life style that aggravates a lack of mental wellbeing. They need to be encouraged and educated do more physical exercise, keep socially connected, keep their brains active, reduce their weight, stop smoking or the harmful use of alcohol, and control their blood pressure, blood sugar and cholesterol levels. Most of these are plausible interventions for a good proportion of the older adults in the world.

## Acknowledgement

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# **MENTAL HEALTH of OLDER ADULTS**

*A Day to Reflect on the*

# **MENTAL HEALTH AND WELLBEING OF OLDER PEOPLE**

*Around the World*

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## **Mental Health in Older People: a Public Health Issue**

The World Health Organization definition of health is “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (1). This means that mental health is essential to overall health and wellbeing, and should be recognized in all older persons with the same importance as physical health.

By 2050, the world population over the age of 60 is estimated to be 2 billion (2). A rapid growth of older persons will occur in low- and middle-income countries (LMICs) with huge consequences for these vulnerable economies (3). Many people live a long and happy life without any mental health problem, and despite the all-too-prevalent image of elderly people being sad, slow, and forgetful, mental disorders are not an inevitable consequence of ageing. Nevertheless, one of the possible negative consequences of the rapid ageing of the global population is the increase in the number of people with mental disorders which will soon overwhelm the mental health system in many countries (3).

More than 20% of people age 55 years or older may have some type of mental health problem (4). Biological changes may interfere with the brain’s functioning. Social changes can lead to isolation or feelings of worthlessness. Somatic diseases are often important contributory factors too. Mental disorders may exacerbate the symptoms and functional disabilities associated with medical illnesses and increase the use of healthcare resources, length of hospital stay and overall cost of care (5).

Mental health problems can have a high impact on an older person’s ability to carry out the basic activities of daily living, reducing their independence, autonomy, and quality of life. The first step to reduce these negative consequences is simply making a diagnosis. Unfortunately, too often mental health problems are undiagnosed and untreated and many older people struggle on without the proper help – or any help at all (5).

Today’s older adult population is unlikely to acknowledge mental illness or access mental health services. Many stigmas exist regarding the meaning

of mental illness. Some older people view mental illness as a sign of weakness and are unlikely to admit to problems, especially when they fear loss of independence. Too many persons consider that symptoms of dementia and depression are a normal part of ageing. Many elders lack availability of services or access to them (6).

Other difficulties concern the work force: few mental health providers have had specialized training in providing care for older adults, and many come with a set of societally-transmitted biases themselves. This therapeutic pessimism allows health professionals to believe that older people cannot change and that it is too late for psychiatric care. Consequently there are few investments in the development of policies, strategies, programmes, and services for older persons with mental health problems (3).

### **Mental Health Problems in Older Adults**

#### ***Dementia***

Dementia describes a group of related symptoms, where there is ongoing decline of the brain and its abilities. Between 2% and 10% of all dementia cases start before the age of 65. The prevalence doubles with every five-year increment after age 65. The number of people with dementia in 2011 around the world was estimated to be 35.6 million, and this number will grow quickly: numbers will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050, with the majority of these persons living in LMICs (3).

Dementia is the leading cause of dependency and disability among older persons. The estimated worldwide cost of dementia is estimated to have been \$604 billion USD in 2010, with direct medical care costs only contributing to 16% of the global cost. Dementia profoundly affects the quality of life of people with dementia and their caregivers (3).

Unfortunately, there is a lack of awareness and understanding of dementia in most countries. This affects the support for those concerned in a number of ways. Low awareness levels contribute to stig-

matization and isolation. Poor understanding creates barriers to timely diagnosis and to accessing ongoing medical and social care, leading to a large gap in treatment. Lack of awareness also takes its toll on the resilience of the family unit and increases financial and legal vulnerability. At a national level, the lack of awareness and lack of infrastructure for providing good and early support increase the likelihood of high costs in supporting increased dependence and morbidity. Although no treatments are currently available to cure dementia, there is much that can be offered to support and improve the lives of all people concerned (3, 7).

There are more than 100 different diseases causing dementia. Alzheimer's disease probably accounts for over 50 percent of cases of dementia. Vascular dementia is also very common. Other types of dementia include Lewy body dementia, frontotemporal dementia, and Wernicke-Korsakoff syndrome as a result of alcohol abuse (3).

#### ***Depression in the elderly***

Depression is the most prevalent mental health problem among older adults. It is associated with distress and suffering and can lead to impairments in physical, mental, and social functioning. The presence of depressive disorders often affects the course and complicates the treatment of other chronic diseases. Older adults with depression visit the doctor and emergency room more often, use more medication, incur higher outpatient charges, and stay longer in the hospital. Although the rate of older adults with depressive symptoms tends to increase with age, depression is not a normal part of growing older (5, 8).



There are symptoms which are more typical in older people; they often do not actually complain of low mood but become anxious, fearful, and lacking in confidence. Anxiety is a warning sign for depression in the elderly. Older people may also express their low mood through complaints about physical symptoms – especially pain. Confusion and forgetfulness are other common symptoms of depression in old age. Social factors often underlie depression in older persons, especially losses, difficulties in socialization which lead to isolation, and sometimes even boredom after retirement (8, 9, 10). The risk of suicide is very high among older men in almost all cultures (11, 12).

In the majority of cases depression in older persons is a treatable condition. As with younger people, treatment consists of a combination of antidepressant drugs and supportive counselling or other forms of psychotherapy. It is also important to rule out physical causes of depression and avoid other treatments able to cause depression (9, 10).

### ***Anxiety in the elderly***

Anxiety, panic, and phobias disrupt the lives of 10% of older persons. Fear is a normal emotion, but sometimes it gets out of control and interferes with the ability to do even simple things. Anxiety is also often a sign of depression in older people and can amplify the physical symptoms related to low mood (13, 14). Cognitive behavioural therapy and drug treatments, including some which work on both anxiety and depression, can also be useful (13, 14).

### ***Other common mental health problems in the elderly***

Most mental health issues can occur at any age so conditions ranging from bipolar disorder to obsessive compulsive disorder, addiction, and less commonly, schizophrenia, may develop. Psychotic disorders, characterized by a loss of contact with reality, may be common in people in their later years, causing hallucinations, abnormal beliefs, and impaired insight. They may be caused by many medical conditions such as dementia, infections, metabolic or hormonal disorders, sensory impairments, and substance abuse. Psychosis may trouble

up to five percent of the elderly in the community and much higher numbers in nursing homes (15, 16).

### **Mental Health and Wellbeing in Older Persons: The Way Forward**

Ageing well in physical and mental health is a right of all persons. Such rights extend to enjoying active and satisfying social lives, participation, having equitable access to good quality health care and social systems, and providing adequate support to caregivers.

The ageing shift will have profound consequences for the workforce, healthcare systems, informal and formal caregiver capacity, and society. It will require more and better strategies to ensure good mental health and wellbeing in the growing older population. The negative stereotypes and negative attitudes against ageing and older people must be stopped. The balance between vulnerability and resilience is central in mental health promotion, and certain groups with specific burdens face a higher risk of poorer mental health. Older women often face specific risks which increase their vulnerability both as sufferers of mental health problems and caregivers. Policies to support them and interventions to prevent mental health problems and isolation in older women must be strengthened (17).

Interventions to prevent social isolation and loneliness are effective measures. An increase in social inclusion and participation of older people must be a very high priority in order to promote active ageing and quality of life in a holistic way by addressing:

- Life-long learning, training, and education of older people
- Psychological and behavioural determinants of health
- Socio-economic determinants of health
- Taking cultural and spiritual needs into account.

Mental health promotion research related to older people should be strengthened in order to improve scientific evidence and should concentrate on issues where the evidence base is weakest. The promotion

of an appropriate use of medication is crucial for optimal mental health and functioning among older people (17).

## Conclusion

In conclusion, the promotion of healthy ageing in all its aspects is an important role for all societies. Early recognition, diagnosis, and treatment of mental disorders that are common in old age are important to prevent avoidable suffering and disabilities.

Care for older adults with mental illness requires sensitivity and observational and relational skills in order to help the older person achieve and maintain the highest possible level of function and wellbeing. Those who care for older persons should always be protected and supported in their tasks everywhere.

All these actions together can certainly contribute to better mental health in old age.

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## *More About*

# DEMENTIA & OLDER ADULTS

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### **What Is Dementia?**

As we progress into old age, it is not uncommon to experience more frequent episodes of forgetfulness. Older adults report lapses in memory such as temporarily forgetting the name of the movie they just saw or the name of a nearby street that is familiar. They can also be vulnerable to confusion in thought processes when, for example, they need to recall complex experiences or medical conditions. If such occasional lapses in memory or thought do not interfere with daily activities or interpersonal relationships, they should be considered a normal consequence of ageing. However, lapses in thought and memory that interfere with normative activities of daily living or interpersonal relationships may signify a clinical syndrome known as dementia. It is important to distinguish between normal forgetfulness and more serious memory problems of dementia.

Dementia has been found to be a principle factor for institutionalization, disability, and shorter survival in older individuals (Qiu, De Ronchi, & Fratiglioni, 2007). Dementia may be understood as a non-specific neuro-degenerative syndrome where accelerated deterioration within two or more functional areas of cognition occurs. This functional deterioration is not accounted for by normative factors of ageing. Areas of accelerated functional deterioration are typically observed in memory, language, emotional control, problem solving ability, and judgment (Qiu, Kivipelto, & Von Strauss, 2009; Toseland & Parker, 2006).

### **Risks Factors Associated with Dementia**

While older age and genetic predisposition have been well established as risk factors for demen-

tia, various other acquired medical conditions can increase risk for it (Kaplan & Berkman, 2011). Approximately 60-80% of cases of dementia are attributed to a neuro-degenerative disease known as Alzheimer's (Cereda et al., 2013). A number of other neuro-degenerative diseases such as Parkinson's and Huntington's disease also cause dementia. In these cases, the function or structure of neurons in the brain slowly begin to degrade or atrophy. Various other diseases and disorders that cause dementia may do so by directly damaging brain tissue. Vascular conditions such as stroke, and chronic vascular factors such as high blood pressure and elevated cholesterol have also been implicated in both the onset and acceleration of dementia (Qiu et al., 2007; DeCarli, 2004). In addition, viral infections such as syphilis, HIV, or Lyme disease; bacterial infections such as tuberculosis and meningitis; demyelinating disorders such as multiple sclerosis; traumatic brain injuries; tumors; and drug use can also cause dementia (Emre, 2008). Psychosocial factors such as poor social networks or reluctance to engage in social networks, and poor physical activity, have also been associated with increased risk for onset of dementia (Qiu et al., 2007).

### **Diagnosing Dementia**

Dementia is a non-specific syndrome with respect to domains of cognitive impairment, and a diagnosis of dementia can only be made after ruling out other factors. A diagnosis of dementia must present deficits in cognitive functioning in two or more domains that are more severe than mild cognitive impairment (MCI) (Emre, 2008). That is, deficits in cognitive functioning must disrupt normative functions of daily living. As noted earlier, deficits in domains of cognitive functioning may encompass



but are not limited to memory, language, emotional control, problem-solving ability, and judgment (Qiu, Kivipelto, & Von Strauss, 2009; Toseland & Parker, 2006). Also, other primary psychiatric disorders such as obsessive-compulsive disorder or depression should be ruled out as the cause of disruptions in normative functions of daily living.

### **If you think you or a loved one may have symptoms of dementia**

It is important to remember that older adults may believe that memory loss and significant functional impairment are a normal part of ageing. As such, many older adults may remain silent about their suf-

fering, needlessly living with an undiagnosed condition and receiving inadequate or no treatment (John A. Hartford Foundation, 2011). If you think you or a family member may be showing signs of dementia you should schedule an appointment with your doctor. The Alzheimer's Association (2013) explains that earlier detection will allow you to:

- Maximize benefits of available treatments.
- Have more time to plan for the future for you and your family.
- Establish care and support services to maximize quality of life for both the individual showing signs of dementia and family members.

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# *A Guide to Mental Wellness in Older Age:*

# **DEPRESSION & OLDER ADULTS**

## **How to Use This Depression Recovery Tool Kit**

*The Geriatric Mental Health Foundation* is pleased to provide you with a depression recovery tool kit online - *A Guide to Mental Wellness in Older Age: Recognizing and Overcoming Depression*. The purpose of this kit is to help consumers, in partnership with their health care providers, identify and treat late-life depression.

The message is simple: late-life depression is treatable and recovery is possible. The first challenge in treating depression is identifying the illness and seeking help. You are not alone. Many people experience depressed moods at some point in their lives. When these experiences become severe or last over a period of time, you may be suffering from a depressive illness. Some people won't tell anyone what they are experiencing; they are afraid that others may not understand, will not take them seriously, or will blame them.

But, the first step to recovery is to tell someone what you are feeling. That person could be a long-time friend, family member, health care provider, or spiritual advisor. They can help you get the assistance you need to feel better. Get treatment now—before it gets worse.

If you are a health care consumer (patient or family member), we urge you to take this material to your health care provider so you can discuss your symptoms and receive the best treatment.

If you are a health care provider, we encourage you to use these materials in your patient education efforts. You may want to give the entire kit to your patient and his or her family member when your patient is first diagnosed. Or you may want to provide different fact sheets as treatment progresses and the patient and their family members require additional information about the illness.

This recovery kit contains a series of fact sheets, listed below, and resource material to help you get better.

- What is Late-Life Depression—The Facts
- Am I Depressed?
- Getting Good Medical Care—Talking to Your Physician About Depression
- Treatment Options for Late-Life Depression
- Taking Care of Yourself—Healthy Lifestyle Choices
- Monitoring Your Symptoms of Depression
- Caregiving—The Role of Family Members and Friends
- Paying for Mental Health Services under Medicare
- Resources

Find the full toolkit at:

**[http://www.gmhfonline.org/gmhf/consumer/depression\\_toolkit.html](http://www.gmhfonline.org/gmhf/consumer/depression_toolkit.html)**

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# *The Role of* **SOCIAL INTERVENTIONS AND REHABILITATION** *in the Care of Older Adults*

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## **Introduction**

There is a global movement towards ‘successful ageing’, and a model of care aimed at maximizing health, wellbeing, functional capacity and social participation in old age. Psychosocial interventions have the ability to improve wellbeing, functioning and promote social rehabilitation in older adults with health problems such as dementia, depression, and frailty. Cross-national research must continue to develop methodologies and improve implementation and effectiveness of psychosocial interventions. This is crucial to establish a sustainable and cost-effective infrastructure to facilitate better health and quality of life in old age.

## **The impact of ageing**

The world population is ageing. It is estimated that between 2010 and 2050, the number of individuals aged over 65 years will rise from 524 million to 1.5 billion (World Health Organization, 2011). The proportion of those aged 85 years and over is also rising rapidly, leading to increased numbers of frail older adults. A consequence of an ageing population is an increased prevalence of dementia. It is estimated that there will be 115 million people living with dementia worldwide in 2050 (Alzheimer’s Disease International, 2010 ).

For years, ageing has been associated with a decline in cognitive, functional and social domains. Losses include reduced cognitive resources, functional capacity, and mobility difficulties often associated with loneliness, dependence, and social isolation. However in recent years, a more positive approach towards ageing has emerged that recognizes the possibility for change. The term ‘active ageing’ refers to ageing as a positive process (World Health Organization, 2002). Baltes & Baltes (1990) presented a model of ‘successful ageing’ involving adaptation, selection, optimization and compensation. Nygren et al. (2005) found older adults to have inner strength, such as resilience, sense of coherence, purpose in life and self-transcendence, which can contribute to better health.

Ideally, health and social care should work towards ensuring that longer life is accompanied by a longer period of health, wellbeing, and independence. It is therefore important to establish ways to maximize the health, wellbeing, and functional capacity of older adults, and promote social participation. This approach towards ageing highlights the potential of psychosocial approaches to improve the functioning and wellbeing of older adults as well as the potential for social rehabilitation.

### **The role of psychosocial interventions**

Social participation is an important component of healthy ageing. It involves social contact and engagement in meaningful activities. Socially active older adults have improved quality of life, health, and wellbeing, and are less likely to be depressed or isolated (Perrin & May, 2001). Psychosocial interventions such as cognitive, behavioural, and supportive interventions can facilitate more active ageing and rehabilitation in older adults. The importance of social participation in older adults will be reviewed in the context of three major health problems: dementia, depression and frailty, considered in both home and care home environments.

### **Dementia**

Kitwood and Bredin (1992) laid the foundations of the psychosocial approach to dementia care, recognizing that despite the inevitable decline, personal growth and wellbeing are possible. More recently, the biopsychosocial model for dementia care (Spector & Orrell, 2010), draws on Kitwood's work to highlight the problem of 'excess disability' when people's current cognitive, functional or social performance is limited by confounding factors. The model describes how excess disability can be reduced by identifying and managing each of these factors, leading to adaptation and improvement. With greater understanding of the psychosocial approach to dementia care and the limited efficacy of pharmacological approaches, a new generation of psychosocial interventions aimed at improving wellbeing, quality of life, cognitive and behavioural functioning have been developed (Woods & Clare 2008). Psychosocial interventions can provide a

cost-effective contribution to dementia care, with some demonstrating similar efficacy to pharmacological approaches (Olazaran et al., 2010).

Psychosocial interventions may be effective in improving cognition, mood, behaviour and quality of life in people with dementia, as well as delaying institutionalization (Olazaran et al., 2010). A home-based occupational therapy programme in the Netherlands used a social intervention involving the patient, carer and occupational therapist to promote independence and meaningful activity in people with dementia. It was shown to be cost-effective and improved ability to carry out activities, mood and quality of life (Graff et al., 2006). Reminiscence, involving peer and family participation has been widely used in dementia care in both the community and care homes (Woods et al., 2006). Its popularity stems from its use of enjoyable activities to promote communication and wellbeing. Group cognitive stimulation therapy is also widely used and has been found to have benefits for cognition and quality of life and to be cost-effective in dementia care (Spector et al., 2003).

Many older adults with dementia live in care homes. Activities that are highly valued by people with dementia can include reminiscence, family & social activities, and musical activities (Harmer & Orrell, 2008). Positive outcomes have been associated with behaviour management techniques, cognitive stimulation and physical activity in care homes (Vernooij-Dassen et al., 2010). Psychosocial interventions found to be beneficial often involve stimulated conversation, enjoyable activities to enhance relationships (e.g. music, dance), and meaningful and reminiscence activities such as sharing memories (Lawrence et al., 2012).

### **Depression**

Depression in older adults can be associated with reduced functional ability, dependence, social isolation, and loneliness (Forsman et al., 2012). Cognitive behavioural therapy and pharmacological approaches have shown efficacy in treating depression in older adults, although medication use is limited by non-compliance and side effects. With grow-

ing evidence that social participation can improve mental health in older adults, psychosocial interventions may provide an attractive option in the care of depression. Psychosocial interventions aimed at promoting social contact (Forsman et al., 2012) or social relationships (Kraaij & de Wilde, 2001) may help prevent depression in older adults.

Physical activity is important for depressed older adults living in the community or care homes, having health benefits and protecting against depression. Singh et al. (2001) found that exercise was safe and effective in reducing depression in older adults, promoting a more positive attitude towards the ageing process. Reminiscence therapy is also a well-established form of depression treatment in older adults in the community and care homes (Pinquart et al., 2007). It can be effective for depressed older adults residing in the community (Watt and Cappellez, 2000) and in care homes (Karimi et al., 2010).

Depression is common in older adults in care homes and can be related to unmet psychosocial needs. Social activities demonstrating benefits were: the provision of new social roles to increase feelings of appreciation, creative activities (e.g. singing, gardening) to provide a sense of belonging, and family-like meal times to enhance social interaction and independence (Forsman et al., 2012).

### **Frail older adults**

Many older adults living in the community and care homes are frail and experience functional difficulties associated with negative mental, physical and social outcomes. Losses associated with frailty in older adults include reduced social participation, social isolation, loneliness and reduced quality of life.

Fear of falling is common in older adults in the community, and is associated with social isolation and reduced social participation. (Tennstedt et al. 1998) found a community-based group intervention involving role play, exercise training, and problem solving reduced fear of falling and increased levels of intended activities and social function in older adults.

There is growing recognition of the benefits of technology for frail older adults in care homes and the community to reduce social isolation and loneliness. Frail older adults living in the community or care homes, when trained to use the Internet, experienced improved wellbeing and empowerment (Straka & Clark, 2000). For frail older adults residing in care homes, the involvement of family members is important for social support (Maas et al., 2004). A video-conference intervention involving interaction with family members reduced loneliness and depression in Taiwanese older adults (Tsai et al., 2010).

### **The future of psychosocial interventions in the care of older adults**

To facilitate a transition into old age with dignity and wellbeing, research is crucial to determine which psychosocial interventions are useful and provide best value for money. This will include an assessment of the comparative effects of interventions to develop methodologies, and improve implementation and effectiveness. Not only is the development of existing psychosocial interventions crucial but it is also vital to take advantage of technological advances in designing new interventions.

Today, social network sites (e.g. Twitter, Facebook and Skype) and email are routine methods of communication that make it possible to socialize from within our own homes. This technology can enrich the lives of older adults at home or in nursing homes by promoting communication, maintaining social networks, and broadening connections. Empowering older adults can help in preventing loneliness and reducing social isolation. Psychosocial interventions involving technology are promising.

Internet training programmes in older adults can facilitate interpersonal interaction and improve independence (Shapira et al., 2007), as well as improve quality of life and reduce social isolation and depression (White et al., 2002). It is important for future psychosocial interventions to move past age-related biases and utilize technological advances in the care of older adults.

## Conclusion

There is a global movement towards 'successful' ageing and a model of care for older adults that focuses on maximizing health, wellbeing, and social

participation in old age. As with dementia care, there has been a shift towards a more psychosocial model of care for older adults, emphasizing the potential for adaptation, rehabilitation and positive change. Psychosocial interventions are an integral component in this model of care to promote active ageing, and they assume a valuable role in maintaining the wellbeing, dignity and morale of older adults. It is vital that cross-national psychosocial research continues to develop psychosocial interventions to establish an infrastructure capable of facilitating better health and wellbeing in old age.

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# *Managing Complexity and Multimorbidity in Older Adults:*

## **TIME TO ACT**

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### **Introduction**

World Mental Health Day 2013 is specifically focused on the elderly, and rightly so. With the improvements in science, technology, social care and environments, more people are living longer and the trend towards an ever-older population is universal. In 2011, life expectancy had already exceeded 75 years in 57 countries of the world (1), and by 2017 the elderly population worldwide, defined as those aged 65 years and over, is predicted to outnumber that of children under 5 years (2).

This change in life expectancy, although welcome, brings its own specific challenges; these include the management of frailty, the prevention of social isolation and loneliness and the management of comorbidity. Thousands of times each day physicians encounter older adults with interacting medical, psychological and social problems and this complexity can sometimes be overwhelming (3). Families and carers require a framework that will enable them to become more confident in dealing with the complex problems and issues that can arise with increasing age, and World Mental Health Day 2013 provides us with an opportunity to make a contribution towards building such a framework.

### **Frailty**

We know frailty is related to age, is highly prevalent in the elderly and contributes to poorer health outcomes, falls, mortality and hospitalization (4–6). Health professionals can screen for frailty by identifying shrinking, in the form of unintentional weight loss and loss of muscle mass, weakness, poor endurance, exhaustion, slowness and low activity (7).

### *Key Message One:*

## **FRAILTY**

- *Elderly individuals should be screened for frailty so that it can be recognized early.*
- *The elderly should be encouraged to participate in dynamic exercises.*
- *Family doctors/general practitioners should have access to community resources that promote exercise.*

Families and carers also need support to understand what frailty is, in order to recognize it early and put in place interventions that preserve as much autonomy as possible in the frail elderly. Interventions such as high-intensity resistance exercise training are effective and help to reduce the risk of falls, functional decline and impaired mobility in people who are suffering from frailty (8).

## Multimorbidity

It is a cause for celebration that an increasing number of people reach the age of 65 years every day (9,10); however, multimorbidity is strongly associated with increasing age and we need to rise to this challenge.

Multimorbidity means that an individual has two or more concurrent long-term diseases. There is a strong relationship between ageing and multimorbidity; more than half of the elderly population suffers from multimorbidity and the prevalence of multimorbidity increases with lower social class. Functional impairment, poor quality of life and increased health costs are a major consequence of multimorbidity (11). In the primary care setting, multimorbidity is inversely related to quality of life, so that the more multimorbidity an individual suffers, the worse their quality of life is (12).

Examples of conditions associated with old age and multimorbidity include malignancy, respiratory disorder, musculoskeletal problems, endocrine disorders, blood disorders, neurosensory disorders, mental health problems and cardiovascular disorders (13).

### Key Message Two:

## MULTIMORBIDITY

- *Multimorbidity affects more than half of the elderly population.*
- *Multimorbidity increases with age and with deprivation.*
- *Increasing multimorbidity is associated with poorer quality of life.*
- *All professionals, families and carers need to be able to recognize multimorbidity, so that holistic health and social care can contribute to improving quality of life in the elderly.*

## Community and social capital and the elderly

Old age is often portrayed as a period of increased social stress, social isolation, frailty, comorbidity and poverty. It can also be a period in an individual's life associated with giving support to others and volunteering for the community. This contributes to community and social capital.

There are many definitions of social and community capital. It can be described as a kind of public good provided by a group or community (14). With increasing life expectancy globally, we need to find ways to capture the social and community capital inherent in this population.

### Key Message Three:

## SOCIAL & COMMUNITY CAPITAL

- *Encouraging older adults to participate in volunteering will increase social and community capital.*
- *Organizations should explore ways to develop a global social and community capital bank.*

The elderly can contribute to social and community capital in many ways. Often people contribute financially – there is evidence that the likelihood of giving to charity increases with age (15). Grandparents across the globe provide many aspects of childcare, such as collecting children from school, support with homework, reading with their grandchildren and imparting the wisdom that is associated with lifelong experience. The elderly also support other elderly people by providing opportunities to maintain social networks by, for instance, running lunch groups, sometimes through faith communities. Contrary to the popular notion of social isolation in later life, older Americans are shown to be well connected to others (16).



The world is also benefiting economically from the expertise and wealth of the generation of baby boomers who are now in their sixties and retiring, and whose contribution increases the value of financial capital (17). The world should therefore look at the elderly not just as net users of resources but as those who have made a significant contribution to national wealth and the stock market. It is predicted that the contribution to volunteering among the baby boomers will also increase with time (18).

One of the tasks in the management of complexity in the elderly is to address stigmatizing attitudes about age and ageing and to encourage the growth of social and community capital. So let us celebrate old age and its positive effects, which include an increase in community wealth, in terms of both finance and time donated to supporting the younger generation as grandparents and volunteers, so improving the quality of learning as well as care.

Schemes have been proposed to capture social capital, such as “time banks” (19). These allow the transference of gains and benefits in a system where the “currency” is hours. This could be a useful tool to enable the elderly to help build community capital; for example, reading to a child in a hospital could earn a token for the recipient to attend a cultural event of his or her choice, using resources never previously tapped.

### **Integrated management**

We already know that an increasing proportion of the population will live to old age, especially in low- and medium-income countries. A transition towards an older society that took more than a century to achieve in Europe is now taking place in less than 25 years in countries like Brazil, China and Thailand (2).

According to the 1997 World Health Organization/ World Psychiatric Association consensus statement (20), good quality care for older people should be:

- comprehensive;
- accessible;
- responsive;
- individualized;

- transdisciplinary;
- accountable;
- systematic.

These key principles apply to prevention, early detection, comprehensive medical and social assessments, evidence-based practice, links with continuing care, social support, residential care and housing, advocacy, spirituality and leisure linked with good specialist and primary care. Fifteen years on, these principles remain pertinent and can be best delivered through an integrated approach (21).

### *Key Message Four:*

## **INTEGRATED CARE**

- *Complexity and multimorbidity in older adults should be managed in a holistic way.*
- *Holistic care in older adults is best achieved through an integrated approach, supported by appropriate policies and protocols.*
- *Primary care has a role in coordinating interventions to achieve desirable health outcomes for the individual.*

An integrated approach (Figure 1) (22) gives an opportunity to provide individualized support to an individual, by:

- working in a transdisciplinary (multidisciplinary) way, by harnessing the wider determinants of health, such as increased opportunities for exercise;
- delivering social care interventions, such as

- avoidance of loneliness and social isolation;
- developing a primary care workforce that is responsive to multimorbidity and able to manage individual needs in a holistic way, and recognizes that multimorbidity in the elderly is the norm;
- recognizing that specialist services, including psychological therapies, will be necessary for some individuals, and are not a luxury.

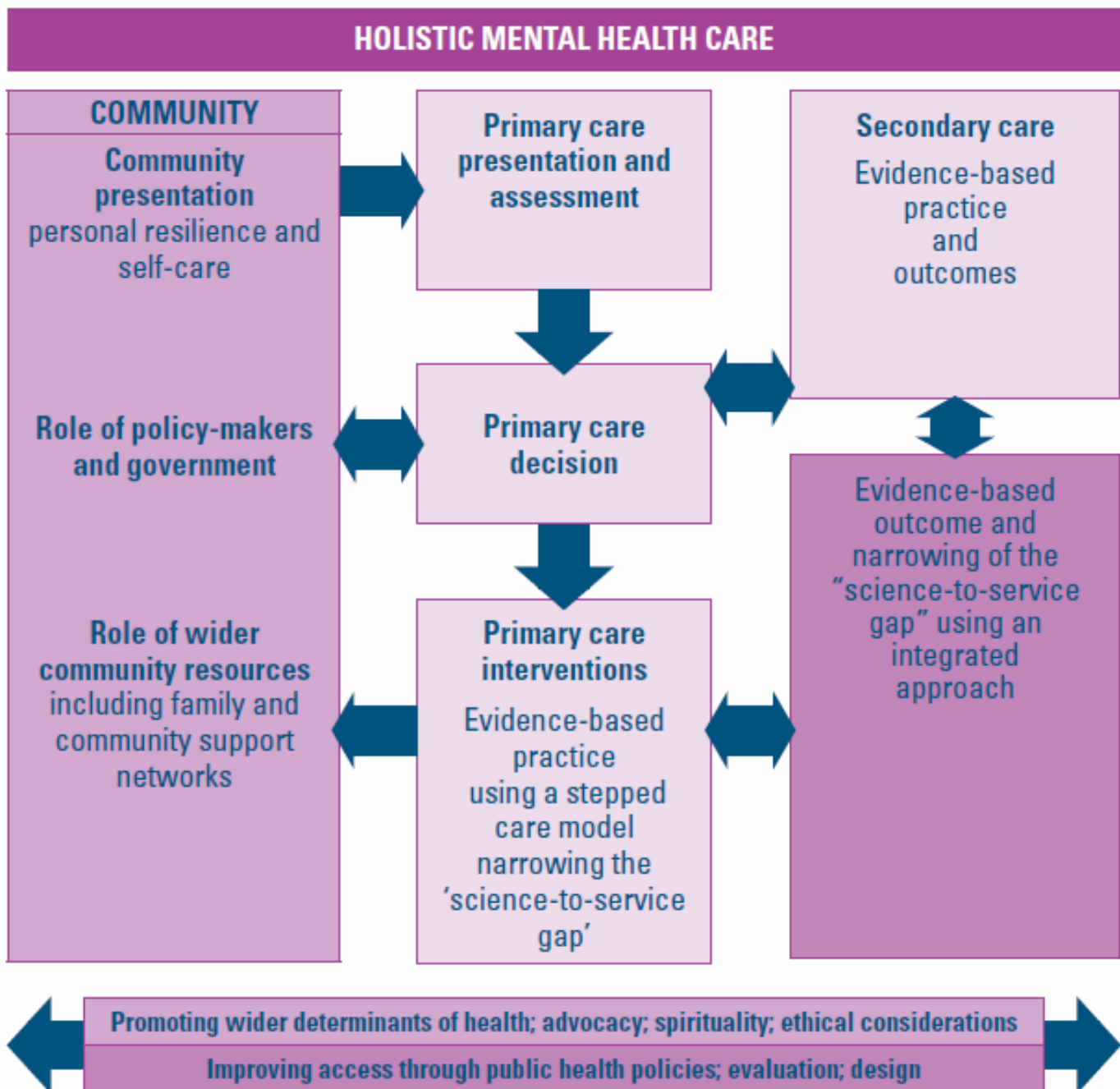


Figure 1: Integrated care: the interrelationships between elements of holistic health care. Reproduced, with permission, from Ivbijaro G. Aims, concept and structure of the book. In: Ivbijaro G, ed. Companion to primary care mental health. London and New York, Wonca and Radcliffe Publishing, 2012:4 (22)

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# *Healthy Ageing:*

# **KEEPING MENTALLY FIT**

## *As You Age*

*Geriatric Mental Health Foundation*

Today, thoughts of ageing gracefully have been replaced by efforts to age successfully. As we age and look forward to longer life expectancies than past generations, we strive to age with good health. How do we do this? By eating nutritiously. Limiting alcohol. Keeping physically active. Staying connected with our friends and family. Seeking medical treatment when necessary. These are the right steps toward healthy ageing. And with good health, we can enjoy life and pursue new dreams and endeavors as we age.

Good health includes both physical and mental well-being. And the two go hand in hand. A healthy mind contributes to a healthy body. The mind, like the body, benefits from low blood pressure, low cholesterol, nourishing food, a healthy weight, and physical activity.

There are many healthy lifestyle choices we can make to keep our bodies healthy and avoid illness and disability. There are additional steps we can take to help preserve healthy minds.

### **What changes in mental abilities can we expect as we age? What's normal?**

As we age, we can expect certain changes in our bodies and minds. We may not see and hear as well as we did in our 20s. We may not be able to remember recent events or details as well or as quickly as we did in our 30s. Beginning in our 30s, the brain's weight, the network of nerves, and its blood flow begin to decrease. Our brains adapt, however, and grow new patterns of nerve endings.

While certain changes in our mental abilities are inevitable as we age, much remains the same. We retain our intellect. Our ability to change and be flexible remains. Old dogs can learn new tricks. We just might need a little more time. We keep our ability to grow intellectually and emotionally.

### **What can I do to keep my mind healthy?**

For the last several years, new research has emerged that shows there are many things we can do to keep our minds healthy. Many of the same things we do to keep our bodies healthy contribute to healthy minds. Physical activity and a diet that helps lower cholesterol levels and blood pressure also help to keep our minds healthy by allowing our bodies to deliver oxygen-rich blood to our brains. In addition, activities that stimulate our minds, like crossword puzzles, reading, writing, and learning new things, help to keep our brains healthy. Staying engaged with the people around us and our communities plays an equally big part in staying mentally fit.

Following are some specific recommendations to keep a healthy mind and ward off mental health problems.

### *Be physically active*

The benefits are numerous. Being physically active helps prevent bone density loss, maintain balance, and ward off illnesses (like heart disease, stroke, and some cancers). For some, illness and disability can bring on or contribute to mental illness. For example, those who live with diabetes, cancer, and heart disease can also suffer from depression.

Regular physical activity helps to:

- Maintain and improve memory
- Maintain and improve mental ability
- Prevent dementia (impaired intellectual functioning) including Alzheimer's disease
- Make us happy and prevent and alleviate depression
- Improve energy levels

*How does exercise do all that?*

Physical activity—whether it's walking, running, swimming, dancing (we have a lot of choices)—helps to:

- Decrease heart rate
- Decrease blood pressure
- Decrease blood cholesterol
- Strengthen the heart and increase the flow of oxygen to the brain
- Improve reaction time
- Improve mobility

If you are thinking about starting an exercise programme, talk first with your doctor. Start slowly, take proper precautions (for example, walk in well-lit areas in sturdy shoes), and have fun. Remember, you don't have to be athletic to benefit from regular physical activity.

## *Keep blood pressure down*

Blood pressure below 120/80 mmHg is considered healthy and helps reduce the risk of stroke, which is tied to dementia including Alzheimer's disease. High blood pressure damages blood vessels, which increases one's risk of stroke, kidney failure, heart disease, and heart attack. Nearly two-thirds of adults over age 65 have high blood pressure, 140/90 mmHg or higher. Those with blood pressure between 120/80 mmHg and 139/89 mmHg are considered to have prehypertension, which means that while the blood pressure is not too high, they are likely to develop it in the future. To reduce or keep blood pressure at a healthy level, keep your weight down, don't smoke, exercise regularly, eat a healthy diet, and limit salt, alcohol and caffeine.

## *Keep your cholesterol levels low*

High blood cholesterol is a risk factor for heart disease as well as dementia. The higher your blood cholesterol level, the greater your chance of disease and illness. An excess of cholesterol (a fat-like substance) in your blood can build up on the walls of your arteries. This causes them to harden and narrow, which slows down and can block blood flow. A blood cholesterol level of less than 200 mg/dL is considered healthy, 200-239 mg/dL is borderline high, and 240 mg/dL and above is high. Heredity, age, and gender can affect cholesterol levels. Cholesterol rises with age and women's levels tend to rise beginning after menopause. Healthy changes to diet, weight, and physical activity can help improve blood cholesterol levels.

## *Eat your vegetables and more*

We've heard it all our lives, the good advice to eat our vegetables. The same diet that can help us stay strong and healthy provides the nutrition necessary for a healthy brain. It starts with a diet rich in fruits and vegetables, whole grains, and nonfat dairy products. Experiment and find out how you best like to eat the good things that your entire body needs. There's an endless variety to suit every taste. Some specific dietary recommendations for a healthy brain:

**Folate** is a B vitamin found in foods such as spinach and asparagus. Folic acid is the synthetic form used in supplements and fortified foods. Folate is necessary for the health of our cells, and helps to prevent anemia and changes to DNA (the building blocks of cells) that could lead to cancer. Folate is also necessary to maintain normal levels of homocysteine, an amino acid in the blood. Good sources of folate and folic acid include fortified breakfast cereals, dark-green leafy vegetables, asparagus, strawberries, beans, and beef liver.

**The vitamins E and C** are important antioxidants found in foods that help guard against cell damage and may reduce the risk of cancer and heart disease. While there's no conclusive evidence, vitamins E and C may help boost mental ability and prevent dementia.

For adults, the recommended dietary allowance (RDA) of vitamin E is 15 milligrams per day from foods. Foods naturally rich in vitamin E include nuts, such as almonds, vegetable oils, seeds, wheat germ, spinach, and other dark-green leafy vegetables.

The RDA of vitamin C for adults is 75 milligrams per day for women and 90 milligrams per day for men. Vitamin C is found in oranges, grapefruits, asparagus, Brussels sprouts, broccoli, bell peppers, collard greens, cabbage, cauliflower, kale, potatoes, spinach, and turnip greens.

### *Monitor your medication use*

Be sure to read labels and carefully follow your physician's instructions. Some medications come with certain precautions such as avoiding alcohol or not combining with other medications, even over-the-counter drugs and herbal remedies. Some memory loss, some forms of dementia, and other problems of the brain can be traced back to harmful drug combinations or inappropriate drug use.

### *Drink moderately*

If you don't drink, don't start. If you do drink, limit yourself to no more than one drink a day if you are over the age of 65 and do not have a drinking problem. One drink is 12 ounces of beer, 1.5 ounces of distilled spirits, or 5 ounces of wine.

### *Give up smoking*

If you are a smoker, don't wait until you are debilitated by a serious disease before considering quitting. Smoking significantly increases one's chance of having a stroke and developing lung and other cancers, emphysema, chronic bronchitis, chronic ob-

structive pulmonary disease (COPD), heart attacks, and peripheral vascular disease.

According to the American Lung Association, when an older person quits smoking, circulation improves immediately and lungs begin to heal. After one year, the additional risk of heart disease caused by smoking is cut almost in half, and the risk of stroke, lung disease, and cancer decreases.

### *Maintain a healthy weight*

People who are obese or overweight are at increased risk for heart disease, high blood pressure, diabetes, arthritis-related disabilities, and some cancers. The health risks of being overweight include high blood pressure, high cholesterol, heart disease, and stroke. Being underweight also carries risks including poor memory and decreased immunity. Ask your health care provider how much you should weigh and for suggestions on reaching that weight. Whatever your weight, a healthy diet and regular exercise will only improve your overall health.

### *Take care of your teeth by brushing and flossing and seeing your dentist regularly*

Recent studies have linked chronic inflammation caused by gum disease to a number of health problems, including Alzheimer's disease and heart disease. So, take care of your teeth not only to maintain a dazzling smile and the ability to chew your favorite foods but also to ward off disease.

### *Keep mentally fit*

Just as we exercise our bodies to keep them in working order, so must we exercise our brains to stay mentally agile and adept. It's the use-it-or-lose-it theory. By engaging in mentally stimulating activities, we can maintain our brain functions as we age. We can continue to grow new connections among the billions of brain cells we possess by learning new things. This activity may help to ward off dementia like Alzheimer's disease. So, work out your

brain daily. Stimulate new areas of your brain and grow more connections among brain cells by intellectually challenging yourself. Solve a puzzle, learn a new musical instrument, read a challenging book, play a board or card game, attend a lecture or play, or write a short story.

## *Reduce stress*

Just as stress can wear our bodies down and increase blood pressure and the risk of heart disease, it can also affect the way we think, our moods, and ability to remember. In fact, the hormones our bodies release when we are under stress may shrink the brain, affecting memory and learning. Stress can also cause or contribute to depression and anxiety.

- To deal with stress, first identify its causes and determine what changes you can make to avoid it. For example, if rush-hour traffic is causing you stress, time your driving or change your route to avoid heavy traffic. If party planning and gift buying during the holidays overwhelm you, simplify and concentrate on those aspects you really look forward to, like getting together with friends and family.
- Talk it out. Sometimes talking through your stress with a friend or therapist, or even writing in a journal, helps to put things in perspective.
- Relax. Whether it's by taking walks, playing golf, hitting a tennis ball, or meditating, find ways to release your stress and take a break.
- Get moving. Physical activity on most days of the week helps our bodies keep mental stress in check.
- Give yourself a break. If you must live with a stressful situation, take mini-vacations. Whether it's 20 minutes or several days, take time to relax and enjoy the things and people you find pleasurable.

## *Protect your brain*

A history of head injury or loss of consciousness can affect the health of your brain. Falls are the leading cause of brain injury in the elderly, according to the Brain Injury Association of America. Take steps to protect your head and the precious matter inside.

- To avoid falls, exercise regularly to improve your balance.
- Clear your home of hazards like clutter on the floor. Make sure you have proper lighting.
- In the car, wear your seatbelt. Ask someone else to drive in situations where you are not as comfortable as you once were, such as nighttime driving or driving in bad weather.
- On your bike, wear a helmet.
- When walking or running, wear proper shoes with good support and stay in well-lit areas.
- If your balance seems a bit unsteady, talk to your doctor about any medications you may be taking.

## *Stay socially connected*

The support we receive from our friends, family, and colleagues helps maintain our mental health. Studies have shown that those who are engaged with family and community groups take longer to show the symptoms of Alzheimer's disease than those who are socially isolated. So stay or become connected. Join a book club or a volunteer group and interact with the world around you.

Look on the bright side. A positive outlook and emotions contribute to a healthy mind and body. Focus on the good in the world and the activities and people that make you happy.

Stay connected spiritually. If nurturing your spiritual side has had meaning for you, keep up that aspect of your life. Those with a strong faith often find support and comfort from their beliefs and their community. So whatever your religious or spiritual beliefs, stay connected. This connection can help prevent and relieve depression and may guard against dementia.

## How can I help my memory?

- Don't expect to remember everything. In today's busy world, we're all overloaded with information. When necessary, use lists, calendars, reminders, and other memory aides. For example, write down appointments on your calendar and keep a list of chores in your pocket.
- Develop routines to help you remember. Take medicines at the same time every day. Leave your keys in the same place.
- Visual memory tends to be better than auditory memory. That is, it's easier to remember what we see than what we hear. Using both at the same time will enhance memory. For example, if you need to pick up fruit at the grocery store, picture blueberries in the produce aisle.
- Associating stories with new things or ideas is also helpful.
- Increasing attention improves learning and memory. When learning something new, limit the distractions (turn off the TV and choose a quiet room), and focus your attention.
- More time helps learning and recall. Allow yourself additional time and have patience.

## What's not normal as we get older? What might indicate an illness?

While some forgetfulness is normal in older age, persistent memory loss is not. And because we experience more loss as we age (family members who move away, the death of loved ones), we are bound to experience more sadness. However, prolonged periods of sadness or depression are not normal as we age.

If you experience any of the following warning signs listed below, or notice that an older relative or friend is experiencing any of these, seek help. Older adults can first start by talking to friends or loved ones, and find help from their family physician, internist, psychiatrist, or geriatric psychiatrist, to name just a few professionals who can provide assistance.

### Warning Signs

The following are not normal characteristics of ageing and can indicate an illness. Discuss these symptoms with your physician.

- Depressed mood or sadness lasting longer than

two weeks

- Unexplained crying spells
- Loss of interest or pleasure in the things and people that were previously enjoyable
- Jumpiness or tiredness, lethargy, fatigue, or loss of energy
- Irritability, quarrelsomeness
- Loss or increase in appetite or weight change
- Sleep change such as insomnia (not being able to sleep) or sleeping more than usual
- Feelings of worthlessness, inappropriate guilt, hopelessness, helplessness
- Decreased ability to think, concentrate, or make decisions
- Repeated thoughts of death or suicide, suicide attempts—Seek help from a medical professional immediately.
- Aches and pains, constipation, or other physical problems that cannot otherwise be explained
- Confusion and disorientation
- Memory loss, loss of recent, short-term memory
- Social withdrawal
- Trouble handling finances, working with numbers, paying the bills
- Change in appearance, standard of dress
- Problems maintaining the home, the yard

## What might trigger or contribute to mental illness?

- Physical disability
- Physical illness
  - With diseases of the heart and lungs, the brain may not get enough oxygen, which affects mental ability and behaviour.
  - Diseases of the adrenal, thyroid, pituitary, or other glands can affect emotions, perceptions, memory, and thought processes
- A change in environment such as moving into a new home
- Loss or illness of a loved one
- A combination of medications
  - On average, older adults take more medications than others. Because our metabolism slows down as we age, drugs can remain longer in an older person and reach toxic levels more quickly
- Drug-alcohol interactions can cause confusion,



mood changes, symptoms of dementia

- Alcohol or drug abuse and misuse
- Poor diet
  - Dental problems can contribute to a poor diet. Some older adults may avoid foods that are difficult to chew.

**If I suspect a problem, what should I do?**

- Talk with your physician. Explain how you feel and describe what is not normal for you. Have a list of all medications, and vitamin, mineral, and herbal supplements.
- Talk to a trusted friend, family member, or spiritual advisor.

**Talking with Your Doctor, Pharmacist, or Other Health Care Providers**

- Have a list of all medications, herbal remedies, and vitamin, mineral and herbal supplements.
- Don't be shy or embarrassed. Explain how you feel.
- Ask questions. Take a list and pencil if necessary.
- Remind your doctors and pharmacist about your medical history.
- Ask for advice and instructions in clear writing, free of medical jargon.
- Ask for a follow-up visit if all your questions cannot be answered during your appointment.
- If you have questions once at home, don't hesitate to phone your doctor.

Mental Fitness Resources

**Alzheimer's Association -  
Maintain Your Brain:**

[www.alz.org/maintainyourbrain/overview.asp](http://www.alz.org/maintainyourbrain/overview.asp)

**AARP Games and Puzzles:**

[www.aarp.org/fun/puzzles](http://www.aarp.org/fun/puzzles)

**Memory Fitness Institute:**

[www.memoryfitnessinstitute.org/default.asp](http://www.memoryfitnessinstitute.org/default.asp)

*The Geriatric Mental Health Foundation was established by the American Association for Geriatric Psychiatry to raise awareness of psychiatric and mental health disorders affecting the elderly, eliminate the stigma of mental illness and treatment, promote healthy ageing strategies, and increase access to quality mental health care for the elderly.*

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# MENTAL HEALTH SERVICE FOR THE ELDERLY IN THAILAND

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## **General Information**

In Thailand, as in many other countries, declines in fertility and mortality over the last three decades have led to a rapid growth in the number of people aged 60 and above. The United Nations Population Fund (UNFPA) reported in 2006 that Thailand ranked as the second “most aged country” after Singapore among the eleven countries of South East Asia, with older persons constituting more than 10% of the population. The proportion of older people will continue to grow. The UNFPA report projected it would reach almost 20% by 2025 and close to 30% by 2050.

## **The Health Situation of Elderly People in Thailand**

During the early 1990s, the health problems commonly found were pain, malnutrition, and anemia. Now degenerative diseases, e.g., cerebrovascular disease, osteoarthritis, hypertension, diabetes, coronary heart disease, dementia and cancer are commonly found among the Thai elderly. Chronic diseases can lead to disability, resulting in a dramatic change in the pattern of their health problems.

The prevalence of long-term disability (6 months or longer), total disability (long-term plus short-term) and dependence status in self-care activities is high. Thai elderly women have a higher prevalence rate of disabilities and dependence than men in all age groups. The rate of disabilities increases with age (long-term disabilities: 17% for male, 20.2% for female).

## **Government Policy**

In 1998, a Bill on Older Persons was proposed in Parliament. After much consultation and redrafting the Act on Older Persons was passed in 2003 and came into force on 1 January 2004. A National Commission on the Elderly, established under the Act on Older Persons, is presided over by the Prime Minister, and serves as the national focal point for policy on the elderly. Its objectives are to provide the elderly with general knowledge on changing age and environmental conditions, including health care; to provide them with protection, family and community care and welfare services as needed; to recognize and support their roles in family and other activities; and to emphasize the responsibility of society for elderly people.

## **Role of the Department of Mental Health**

The Department of Mental Health has responsibilities for mental health promotion for older citizens. Its objectives are:

- To enable older people to prepare for quality ageing;
- To promote positive attitudes toward the elderly;
- To promote and support the participation of older people in community activities.

The Ministry of Public Health has supported the establishment of clubs for older people and offered a wide range of health promotion activities (exercise classes, lectures on health and mental health care, cultural activities) in every sub-district. The Department of Mental Health contributed to these initia-

tives by developing a self-learning mental health promotion manual and distributing it to every club. A manual for running the clubs was also developed to keep the activities sustainable.

To promote a positive attitude toward older people the Department of Mental Health wanted them to be viewed not as a burden but as valuable contributors to society. The Department encouraged the clubs to provide training in simple counseling techniques so that their members can help people in the community with problems. Also, training is provided on how to communicate with young children, to help older people assist their families in educating their grandchildren.

Since older people have various social assets they can pass on to the next generation, training is given on how to transfer knowledge to younger people. This activity encourages pride and self-esteem. Knowledge about mental health is also provided, so they can take care of their own mental health and that of people around them.

A main purpose of the Elders' Clubs is to encourage older people to participate in social activities. The Department of Mental Health has strengthened this aspect by encouraging the clubs to set up self-help groups in which members help and support each other. These activities include visiting permanently homebound older people, or visiting members at home when they are ill. The Department developed a home visit manual to enable club members to provide information to the people they visit, or their family members or caregivers.

In Thailand, the population is predominantly Buddhist (about 94-95%) and the temple is a community center where people, especially the elderly, gather in large numbers to join in religious activities. In order to cooperate with religious institutions in providing spiritual support to older people in an appropriate way, the Department of Mental Health provides information about mental health and simple counseling techniques to the monks so that they can pass on knowledge in their own words.

Recently the Department of Mental Health developed a sixteen-week programme to support five aspects of the wellbeing of older people—health, recreation, integrity, cognition and peacefulness. A manual of recommended activities has been published for each of these five themes, and assessment tools were developed to evaluate the effectiveness of the programme. So far the programme has been introduced as a pilot project in six provinces, and the assessment tools show that it is effective and useful for older people in three groups—those with limited social contacts, those who are homebound, and those who are bedridden. The programme will now be implemented throughout the country.

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# *Person-Centered Care For Older Adults -* **THE “CULTURE CHANGE” MOVEMENT**

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The author believes that the best housing for older people is their own home, with the aid and support of family members and home health care personnel. However, once their needs become greater than the ability of home care to serve them and the capacity of the family to provide informal support, they should be able to move to a group living arrangement where they or their family members can maintain as much control as possible over their life. This setting should include emotional support, social engagement, intellectual stimulation and independence within a residential context.

Culture Change is a movement for the transformation of older adult services, based on people-directed values and practices such as choice, dignity, respect, self-determination and purposeful living. It enhances the quality of care and provides the kind of life for seniors which they would experience if they were still living in their own home. The residents are able to continue to live life on their terms; they receive the right amount of care at the right time, including individual, unanticipated needs. This approach is focused on customer service and hospitality and aims to enhance the satisfaction of residents, families, and staff members as well. The caregivers are permanently assigned to a particular group of residents as members of self-directed work teams. Rather than working in a single department, such as nursing, housekeeping, or food service, staff functions are blended so that all staff members can help residents with their personal care, lead activities, and do cooking and light housekeeping. Studies show that when care is person-directed, residents

tend to be healthier and more independent. According to Robyn Stone, executive director of the Institute for the Future of Ageing Services at the American Association of Homes and Services for the Ageing, “caregivers find their jobs more satisfying when they are intricately involved with care planning and decision making”. Caregivers develop new skills and deepen existing relationships with the residents.

Culture Change responds to the acute need for research that investigates ways to change the fundamental beliefs, values, attitudes and standards of behaviour that currently shape the standard of care for nursing home residents with dementia. Over the past decade, a significant amount of work has focused on improving the quality of care and the quality of life for long-term care residents. The issue of the “culture of care” has become a central point in attempting to reform nursing home care for the elderly. It has become increasingly clear that factors which have a negative effect on the quality of life for nursing home residents generally exert a particularly disabling effect on residents with dementia due to their multiple cognitive and functional disabilities. The new culture of care emphasizes the uniqueness, experience and accomplishments of both the individual with dementia and the person who gives them care, and the development of a personal, respectful, caring relationship between them. Experience has demonstrated that if change in the culture of dementia care is to occur in the nursing home, a catalyst for change or a change agent must step forward to identify the new vision of care and to take responsi-

bility on a continuing basis for the process of culture change in their facilities. The change agent must be a leader, i.e. a person with interpersonal and intellectual resources, respected by co-workers, who can inspire confidence and convey a sense of steady leadership in a changing workplace.

A neighborhood model of person-centered care offers smaller units (8-20 residents), consistent staff assignments, separate dining and living room areas, and local decision-making. Residents can choose when to retire; when to get out of bed; what, when, and where to eat; and the activities in which they wish to engage. The nursing assistant-to-resident ratio is one to five. An important key principle of culture change is a “homelike” environment in which lifestyle choices can be freely made. Being at home means an existence that offers choices. Nursing homes invested in the culture change process report significant improvement in staff retention and reduced turnover (from 65-100% prior to culture change to 30%, annually).

The elderly person’s family is a very important part of the concept. Relatives should be welcome to come at any time and to stay as long as they want; to share a meal, participate in daily activities, celebrations, etc. The communities have areas for socializing and entertaining. Professionals have developed many activities in order to support the residents in maintaining their cognitive, educational, social, physical, and spiritual well-being. The elderly should have the choice to attend offered group activities or individual activities that are of interest to them. The caregivers should have the desire to help the residents gain new experiences and skills and to enable and encourage them to remain active physically and mentally as well as continuing to interact socially with their peers, family and friends.

The professional caregivers’ team is an essential component of this unique approach to providing care. Each of them should understand the concept of care and be responsible for the well being of the elderly members of the family. It is also important that they understand the special physiological, psychological, and social needs of the aged and

possess personal characteristics such as enthusiasm, patience, courage and tolerance. To instill a feeling for family in the elderly, it is important that caregivers also feel like they are at home. There should be a calm and friendly relationship among the team, with support groups for sharing experiences and encouraging inter-personal growth, such as reviewing new educational modules and case studies – their leaders should ensure that everyone on the team feels confident, secure and satisfied in performing within the community.

Person-centered care is a change in philosophy, leadership, and management style that can reverse the assumption that decline and illness inexorably occur with ageing. About twenty years ago, a small group of prominent professionals from the field of long-term care came together to propose a radical change in the culture of ageing. They wanted to ensure that when seniors go to receive care in a community-based setting, it is to thrive, not to decline. This movement, away from institutional provider-driven models to more humane consumer-driven care that embraces flexibility and self-determination, has come to be known as culture change.

Over the past decade, the culture change movement has begun to attract many long-term care providers beyond those who were among the early adopters of the reforms. As more nursing homes engage in culture change efforts, providers have raised concerns about federal and state regulations and practices that they view as barriers to successful implementation. According to them, the traditional nursing home regulatory approach, which uses survey and enforcement to achieve performance improvement, has



created tensions between providers and surveyors; it has had limited success in improving quality overall and has not necessarily allowed innovation to grow. This has been the perception of many homes wanting to undertake transformative “culture change” reforms. To move toward a new model of nursing home regulation, the states and federal government must strike a balance between the traditional regulatory approach to weed out substandard facilities and a partnership model aimed at promoting high performance. Regulators, providers, consumer groups, residents and their families also will need to commit to the principles of person-centered care to ensure the success of the new collaborative approach.

Most administrators and staff are afraid to pursue culture change activities that they believe may put them in jeopardy. Others indicate that specific regulations actually get in the way of culture change, particularly those that prevent necessary changes to the physical environment, staffing patterns, and training requirements. A recent study of state culture change initiatives funded by The Commonwealth Fund found substantial evidence of perceptions by providers that regulations can impede culture change. It also identified several states that have developed a more collaborative relationship between regulators and nursing home providers to facilitate successful culture change efforts.

In 2002, the Centers for Medicare and Medicaid Services (CMS) trained surveyors on indicators of culture change and how nursing home routines might begin to look different from standard practice. The Medicare-funded Quality Improvement Organizations (QIO) included culture change initiatives in their 2005-2008 working plans. At least nine states (Michigan, Colorado, Florida, Illinois, Kansas, New Jersey, North Carolina, South Carolina, and Pennsylvania) have formed culture change coalitions that offer guidelines for culture change innovation, networking, communication, guest lectures, and surveyor education programmes. Some are conducting or supporting programme evaluation and workforce research. Several states (Kansas, New Jersey, Michigan, Texas, and South Carolina) have allocated money to nursing homes to implement culture

change.

Culture change in long-term care settings has grown from a desire for a radical departure from the isolating and impersonal nature of traditional institutionalized care to models of care that are empowering and respectful to seniors and staff. With reinforcement from legislation mandating improvements in long-term care, professionals have created a host of change models. Models vary in how they are executed, but they are all based on values and beliefs that return control and decision-making to seniors and their caregivers. Because there is great diversity in the health of residents, these models may be more meaningful to some residents than others.

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# GRIEF AND OLDER ADULTS

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## **What is Grieving?**

At some point in our lives, we all experience the loss of someone dear to us. This loss may include family members, friends, or even pets. The experience of grief is an unavoidable and necessary process that is integral to coping with and moving on from such a loss. Traditionally, the terms bereavement, mourning, and grieving have all been used interchangeably to broadly describe the state or process of loss. These ideas have adopted specific definitions as researchers began to understand what happens to us when we lose a loved one. Zisook and Shear (2009) explain that there is now a general consensus among researchers suggesting that the term bereavement should be used to refer to the fact of the loss, while mourning should be understood as specific behavioural responses within a context of accepted social and cultural beliefs or rituals. Grief on the other hand may be understood as behaviours, thoughts, and emotional responses that result from the death of a loved one.

## **The Experience of Grief in Older Adults**

Previous theories of grief have attempted to define a specific order of stages that we all must experience in order to complete the grieving process. It is now understood that everyone experiences the loss of a loved one differently. Expressions of grief can vary widely in their intensity and length across different cultures and contexts (Zisook & Shear, 2009). Older adults may often experience grief very differently from younger individuals. Older adults may increasingly focus on dying rather than living as they age. Increased dependence on others and illness may also intensify feelings of loneliness and fear when faced with the loss of a loved one (Miller, 2012). Illness of a spouse or the move to a long-term care facility may also serve to trigger the grieving process.

## **Normal Versus Complicated Patterns of Grief**

The grieving process can vary widely in terms of duration, intensity, and across cultures. As such, there is no definitive or single definition of normal grieving. Normative patterns of grieving may include a wide range of emotional expressions, from subdued to intense. Typically, the grieving process begins with what may be characterized as waves of attention where individuals will fluctuate to and from the loss of their loved one (Zisook & Shear, 2009; Miller, 2012). This process may bring about feelings of fear, anxiety, shame, or unhappiness. Over time, many more positive feelings may begin to manifest such as: joy, peace, or happiness linked to memories of the loved one. Experiences of feelings such as these have been found to be associated with a positive outcome (Bonanno, Wortman & Nesse, 2004).

Complicated patterns of grief occur in approximately 10-20% of bereaved individuals (Shear & Shair, 2005; Miller, 2012). In these cases, individuals typically have difficulty accepting the death of a loved one. Intense feelings of separation and traumatic distress last beyond six months (Miller, 2012). Invasive and repetitive intense yearning and longing for the deceased may become consuming; impeding or preventing individuals from completing daily activities. Individuals with complicated grief often believe that they are able to stay connected to their lost love through their ongoing expression of loss and mourning. They may also feel that they are betraying the deceased by enjoying life. Older adults who exhibit early experiences of non-acceptance of the loss of a loved one are more likely to have more intense ongoing grief experiences (Holland, Futterman, Thompson, Moran, & Gallagher-Thompson, 2013).

Possible signs of complicated grief in older adults include:

- Increased sensations of physical pain;
- Increased alcohol consumption and/or smoking;
- Loss of interest in life or social activities (e.g. reluctance to interact with friends and family or engage in pleasurable activities);
- Trouble sleeping;
- Reduced desire to tend to personal care (e.g. missing medical appointments or failing to take medications as prescribed);
- Over-involvement in activities related to the deceased (e.g. persistent visitation to the deceased's grave while ignoring activities of daily living such as maintaining hygiene and grooming);
- Avoiding activities related to the deceased (e.g. avoiding required trips to the market because they bring about intense aversive feelings associated with the deceased).

Grieving is a normal process that does not require treatment. However, when this process becomes complicated and when it interferes with daily functioning lasting beyond six months, it may be helpful to seek treatment. Older adults may be especially vulnerable to needlessly suffering with complicated grief because they or their loved ones may think that nothing can be done (John A. Hartford Foundation, 2011). While the normal grieving process does not require treatment, if a person is having significant difficulty coping with a loss a doctor or mental health clinician should be contacted.

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**CAREGIVERS,  
FAMILY  
&  
OLDER ADULTS**

# *Caring For The* **ALZHEIMER'S DISEASE** *Patient*

*Geriatric Mental Health Foundation*

Alzheimer's disease, a disorder affecting the brain, is the leading cause of dementia. Characterized by memory loss, impaired judgement, loss of language skills, and changed personality, the disease affects not only the patient but also his or her family. The responsibility for caring for the patient often falls on a close family member. This responsibility can take an enormous emotional and physical toll, especially when added to the psychological distress of watching a loved one deteriorate. Because of the burdens of caregiving, the caregiver of the patient is often referred to as the hidden, or second, patient of the disease.

This brochure was designed to help you and your family cope with the devastating illness, diminish the burden of caregiving, and work with your family member's doctor to provide the very best care.

As the disease progresses, an Alzheimer's disease patient will become increasingly dependent upon his or her caregivers. You and your family must also cope with personality changes that can be disturbing. Behavioural and mood disorders, common in individuals with Alzheimer's disease, are the most disturbing aspect of the disease for many caregivers. These disorders include depression, agitation, wandering, and sleep disturbances.

Your family member's physician can help provide much-needed support to you and your family by discussing current needs and how or if they are being met, explaining the diagnosis, and providing information about the disease and available resources. Physicians can also help ensure that problem behaviours are being managed as well as possible and

refer you to specialists for psychosocial support if necessary.

## *Understanding and Recognizing the Special Needs of Families and Caregivers*

Alzheimer's disease can create a significant disruption in a family. Family members' roles and responsibilities change, and each of you may handle these major adjustments differently. Not surprisingly, conflicts may arise. Some members of your family will be eager to understand the patient's disease, and some may deny the problem. The patient's physician will likely be your primary source of information. However, not everyone is comfortable asking a physician questions, even when they want more information.

Keep in mind the following suggestions when talking about the disease with the patient's doctor and other medical professionals. Ask the physician to:

- Use simple everyday language and avoid medical jargon.
- Present the information in small parts.
- Use examples and analogies.
- Provide take-home reading or audio-visual material.
- List other possible sources of information.

You and your family may want to consult such sources as local chapters of the Alzheimer's Association, the Alzheimer's Association website ([www.alz.org](http://www.alz.org)).

alz.org), the Geriatric Mental Health Foundation (www.gmhfonline.org), the American Association for Geriatric Psychiatry website (www.AAGPonline.org) and other web-based resources.

The patient, you, and other family members should:

- Repeat what the doctor says to ensure that you understand the information.
- Take notes if that helps you retain the information.
- Ask questions when you do not understand what was said.
- Contact the doctor later with follow-up questions. Don't expect to absorb all the information at once.

As a caregiver of an Alzheimer's disease patient you may experience a range of natural emotions in response to the disease. These feelings, which may include frustration, anger, fear, and sadness, as well as concerns about your own memory lapses, can be managed by talking with a physician and/or a professional counselor if necessary.

Beyond natural reactions to the disease, you and your family may experience high levels of stress. In fact, up to 50 percent of primary caregivers experience significant psychological distress, including depression. Caregiver stress can present serious health and psychological problems. You and your family should be aware of, and watch for, symptoms such as:

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

*Adapted from Caregiver Stress—Signs to Watch for, Steps to Take, a brochure from the Alzheimer's Association.*

Those experiencing these conditions do not provide the best care to their patients. If you are experiencing any of these symptoms, you should seek treatment for both your and the patient's benefit. Various treatments and techniques can improve the quality of life and wellbeing for you, the patient, and the rest of your family.

For many caregivers, the stress of caregiving eventually causes stress in other areas of life. Numerous studies have linked caregiving of patients suffering from dementia (a loss of intellectual abilities including impaired memory and judgement) to poor physical and mental health and higher use of psychiatric medications. Emotional support from family and friends, self-confidence, and resources to help with household chores all were found to positively influence caregivers and protect against stress.

Those family members who are not involved in primary caregiving also experience psychological effects as a result of a loved one's Alzheimer's disease. Some family members may feel neglected because their needs have become secondary to those of the patient. Children may become confused, afraid, jealous of, or even embarrassed by a family member (usually a grandparent) with Alzheimer's disease. Family counseling can help you and your family work through these emotions and deal with family role changes.

As a normal response, families confronted with Alzheimer's disease may progress through five stages of adjustment: denial, over-involvement, anger, guilt, and acceptance. These responses may occur independently of one another and not necessarily in the following order.

## Five Reactions to Family Adjustment

| Response                | Description   | Help for the Caregiver  |
|-------------------------|---|---|
| <b>Denial</b>           | The initial response that nothing is wrong. Denial can also reappear as false hopes that treatment will cure the patient.   | Information about the disease can help families understand what is happening, and what to expect.   |
| <b>Over-involvement</b> | Attempts to compensate for the illness and its impairments. By being over-involved in the patient's care, the caregiver may refuse help and feel isolated. Sometimes the primary caregiver will try to meet every need of the patient.  | Families should be aware of all of the available options for support, including in-home support services. Caregivers must understand that no one person can meet all the patient's needs. The consequences of over-involvement can be detrimental to the patient.                       |
| <b>Anger</b>            | Anger can occur when the family realizes that attempts at compensation have failed, and physical and emotional burdens begin to take their toll. Long-standing and interpersonal problems and unresolved issues can be troubling at this stage if the root of the anger is not addressed. | Support groups can help families work through feelings of anger and gain empathy from other families. If anger becomes severe, family members may need to be encouraged to enter counseling so that hostility does not stand in the way of patient care or sever important family ties. |
| <b>Guilt</b>            | Developed from anger and "what ifs" brought on by looking back. Unresolved feelings of anger or guilt can lead to depression. Guilt is often experienced when the patient can no longer be cared for at home.   | These feelings are normal responses to extreme stress. It is what caregivers and family members do with their feelings that really matters.   |
| <b>Acceptance</b>       | Resolution or acceptance of the problems. Acceptance comes from a full understanding of the disease and its effect on the family.   | Support, education, and other resources can help families move toward acceptance.   |

## Caring for the Caregiver

Maintaining your own health and stamina is an important part of caring for a patient with Alzheimer's disease. Different psychosocial and behavioural interventions—treatments, activities, and techniques—can help you and the patient by relieving

some of your burden and enhancing patient care. By failing to treat an Alzheimer's disease patient's excess disabilities, caregivers may burn out and choose institutional care for the family member earlier than necessary. In reality, the Alzheimer's disease patient is part of a larger family system,

and a successful management regimen in which the individual's behavioural and mood disorders are controlled can have a profound effect on the wellbeing of all family members.

The behavioural and emotional conditions commonly associated with Alzheimer's disease caregiving tend to respond well to a combination of traditional psychotherapies (counseling) and supporting interventions. Over time, attention to your own mental and physical health can improve your and your loved one's quality of life.

## *Help for Families and Caregivers*

The following psychosocial interventions can help you and your family better cope with and help someone with Alzheimer's disease:

### **Support groups**

Support groups allow family members and caregivers a safe place to share feelings, gain emotional and moral support, learn practical information, and talk with people who can relate to your frustrations. Support groups are widely available for the families and caregivers of Alzheimer's disease patients through local chapters of the Alzheimer's Association, hospitals, senior service organizations, and religious groups.

Studies have shown that the combination of support-group participation, individual and family counseling, and as-needed consultation for primary caregivers are helpful. In one study, nursing home placement was delayed by nearly one year as the result of psychosocial interventions, and caregivers reported fewer illnesses and depression and a greater sense of family support.

### **Respite services**

Respite care can provide you with a scheduled period of relief from the demanding responsibilities of caring for a person with dementia. For periods ranging from a few hours or a few weeks, another person can tend to the needs of the patient, leaving you free to handle other responsibilities or to simply

recuperate and experience some rest and relaxation. Using respite services allows some patients to continue receiving care at home for a longer period before being placed in a nursing home, according to some studies. Companions, home health aids, visiting nurses, adult day care services, and nursing homes provide respite services. Respite can also be provided through the use of videotapes that use professional actors to simulate interaction with the patient or video scrapbooks that show material of interest to the patient.

### **Skills training**

Caring for an Alzheimer's disease patient at home requires special skills that may be new to you. Training programs in the community, such as those provided through the Alzheimer's Association, help caregivers manage Alzheimer's disease patients at home. The manner in which you communicate with the individual with Alzheimer's disease will change as the disease progresses, and developing communication skills to minimize unwanted behaviour is essential. Education about the disease can help you and your family develop these skills and minimize frustration as you learn what to expect.

### **Family interventions for patients in long-term care**

If it becomes necessary to place your family member in a nursing home, counseling may help you and your family deal with feelings of guilt, grief, anger, depression, and anxiety. Support can be obtained through family and group counseling, support groups, and individual therapy, if needed. Your physician can help you evaluate your options, though planning for long-term care should be discussed well before it becomes necessary.

## *Patient-Directed Treatments*

An individual with Alzheimer's disease may exhibit difficult behaviors such as severe mood swings, verbal or physical aggression, combativeness, repetition of words, and wandering. Efforts to maintain or improve the patient's behaviour can help improve the quality of life for the patient, your family, and you. The following techniques are designed to manage the functional and behavioural deterioration of a patient with Alzheimer's disease. These strategies have worked for many families, often delaying institutionalization. Talk with your physician about strategies that may help you.

### **Pharmacological treatments**

Several medications are currently on the market that help to delay the severity of cognitive impairment as well as treat the behavioural symptoms of Alzheimer's disease. Talk to your family member's physician to discuss drug therapy, and consult the American Association for Geriatric Psychiatry for more information.

### **Independence-promoting strategies**

Interventions designed to improve patients' functioning also have been shown to improve Alzheimer's disease symptoms. Such strategies help the patient retain mental and physical abilities and help with daily activities of hygiene, dressing, grooming, and eating. The techniques use incentives, verbal and physical prompting, and physical guidance. For example, having an Alzheimer's disease patient choose the specific activity to engage in for the day promotes independence.

### **Strength/mobility enhancement**

The well-known benefits of exercise apply to the person with dementia as well. Simple stretches, scheduled walking, or peddling a stationary bicycle all can help prolong mobility, decrease agitation, and improve sleep in the mild to moderately diseased patient.

### **Incontinence management**

Monitoring incontinence, scheduling bathroom time, and providing reminders are techniques that can help caregivers manage incontinence at home.

### **Sleep management**

Sleep problems associated with Alzheimer's disease can be a major source of caregiver stress and fatigue. Studies have shown that a period of bright light may decrease an individual's agitation and improve sleep patterns. Other strategies for enhancing nighttime sleep include maintaining a darkened environment at night, providing an early evening warm bath, and limiting daytime napping.

### **White noise**

White noise—continuous, monotonous, soft background noise—has been shown to modestly decrease verbal agitation in some patients. In addition to white noise generators, recordings of ocean waves, flowing streams, or other nature sounds may be soothing for the patient. Music therapy may also help by stirring memories and emotions.

### **Lighting**

Dimming lights at mealtime may decrease mealtime agitation and increase food consumption.

### **Visual cueing**

Visual cueing, such as posting a picture of a bed on the door of the patient's bedroom, can help a person with dementia find his or her way around a home as memory begins to fade. Pictures may provide more effective cues for direction than words.

### **Providing a supportive environment**

Individuals with Alzheimer's disease are highly sensitive to their environment and have a decreased tolerance for stress. Your physician can help you identify environmental triggers (for example, lights that are too bright or uncomfortable room or water temperatures) that may cause behavioural problems and work to eliminate them.

### **Traditional psychosocial therapy**

Counseling can help patients in mild states of dementia reduce anger, anxiety, fear, suspiciousness, frustration, and depression. A mental health professional can provide advice and encouragement and help the patient interpret his or her feelings.

### **Reminiscence therapy**

By receiving encouragement and support from peers, patients can draw upon their long-term memory to recall and share events from their past. Reminiscence therapy often is conducted in group settings but can be used on an individual basis.

### **Validation**

As dementia progresses, caregivers may find that attempts to correct their loved one's misstatements or delusions do more harm than good. Validation is a technique in which the family member or caregiver affirms the patient's attempts to communicate, even if the patient is engaged in a false sense of reality.

### **Simulated presence**

A person with moderate to severe dementia may find comfort in simulated conversations with a close friend or family member when the individual cannot be there in person. A simple audio or video tape recording of the individual recounting past events, with pauses to allow the patient to respond, provides temporary companionship and allows caregivers to attend to other things.

### **Pet therapy**

Petting or watching small pets can improve the mood and behaviour of dementia patients. Pets can be introduced in both group and individual counseling sessions.

### **Recreational therapies**

Recreational therapies include exercises, group activities, and simple games. Tailored to the stage of the disease, these can be excellent stimulation for the patient and can help control problem behaviours.

### **Art therapies**

Art therapies include drawing, collage, coloring, sculpture, dance, and listening to music. These activities provide a creative outlet for the patient to express emotions without talking. Other benefits include mood improvement, sensory and intellectual stimulation, decreased agitation, and improved motor skills.

## *Caregiver Depression*

As a result of the demanding and emotional work, caregivers tend to suffer clinical depression and anxiety more often than the general population. A substantial percentage of caregivers—as many as fifty percent—experience depressive symptoms severe enough to call for treatment. As a caregiver of someone with dementia, you should be aware of the signs of depression and talk to your doctor if you have symptoms. Providing the best possible care for your family member requires that you remain healthy and strong.

The following symptoms in caregivers may indicate depression:

- Aches and pains that won't go away
- Irritability
- Problems with eating and weight
- Tiredness or lack of energy
- Loss of pleasure or interest in activities
- Insomnia
- Feeling empty or sad
- Excessive feelings of guilt

The spouses of Alzheimer disease patients often suffer the most and benefit significantly from long-term social support. When social support fails to reduce the depression, antidepressant medication may be helpful. In fact, treating even mild depression can make a remarkable difference for both you and your patient.

Depression associated with or brought on by caregiving is not necessarily eliminated or reduced when a patient dies. For support after the death of a loved one, you and your family may want to talk with your physician or seek bereavement counseling. On the death of a spouse with Alzheimer's disease, some men experience increased depression while some women improve, according to studies.

## *Helping Caregivers Care for Themselves*

Caregivers who are prepared, knowledgeable, supported, and in good psychological and physical health ultimately provide the best care. You can take the following steps to prepare for the challenges of caring for a dementia patient.

- Learn about the available community resources (adult day care, in-home assistance, visiting nurses).
- Contact the local Alzheimer's Association chapter (the association can help caregivers with caregiving skills and techniques).
- Contact support groups through your local Alzheimer's Association or hospital.
- Ask for help from other family members and friends.
- Attend to your own health.
- Plan ahead for future legal and financial issues.
- Attend to your own advanced planning needs (in addition to advance planning for the patient) in the event you become unable to care for the patient.
- Create strategies for handling medical emergencies that do not rely on the individual with Alzheimer's disease.

## *Referral to Specialists*

Referral to a specialist or specialty Alzheimer's disease center sometimes is necessary. Geriatric psychiatrists, medical doctors with special training in the mental health of older adults, treat both older adults and their caregivers. Geriatric psychiatrists can provide:

- Behavioural management, especially for agitation, psychosis or violent behavior. Management of suicidal behavior or treatment of major depression.
- Individual or family therapy for patients and caregivers.
- Functional evaluation to make a determination about long-term care placement.

Geriatricians can be helpful when there is a mixture of complex medical and behavioural issues, when complex drug regimens need evaluating, and in the assessment of long-term care needs.

Clinical psychologists and advance practice psychiatric nurses (APNs) can provide therapy for caregivers, and social workers can offer counseling and link patients and family members to community resources. Activity and physical therapists provide guidance on appropriate levels of physical and group activity for patients. Occupational therapists can evaluate the patient's ability to perform activities of daily living and offer strategies to maximize functioning.

## *Research and Future Treatment*

Currently much research is being conducted on the nature of Alzheimer's disease that will lead to earlier diagnoses and more effective treatments. Researchers are also investigating methods to better support caregivers to help ease the burden of caring for patients with dementia.



## *Caring for the Patient*

Caring for a loved one with dementia requires talking to the patient's physician, family members, and other caregivers. Effective communication among all will help provide the best care for the patient. Be alert to the stress of caregiving and talk to your physician when stress becomes too much. The emotional stress of caregiving can cause isolation, anxiety, increased physical illness, and depression. Not only are these conditions harmful to you, but they also can be detrimental to the care of the Alzheimer's disease patient. Counseling and behavioural interventions for both patients and caregivers can improve your quality of life and quality of care.

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# COLLABORATING WITH FAMILIES IN THE CARE

## *Of Elderly Patients*

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In all cultures and across time, individuals with health care needs have turned to their families for help. In collectivist cultures, families are usually the primary group responsible for the needs of elderly family members. In individualistic cultures, private health insurance, nursing homes and community-based programmes might provide many services that traditionally have been done by family members. But even in the most wealthy, individualistic cultures, elderly individuals look to their families for support. For the elderly, who often face loneliness, isolation, and a loss of purpose, family members' support can ideally provide a resource that no other group offers – attachment and continuity of bonds.

Several recent trends further influence family interaction in ageing families. In most of the world, people are living longer, and families will be caring for their elderly members for a longer period than any previous era. As the elderly live into their eighties and nineties, they also face living with multiple illnesses including dementia, heart disease, high blood pressure, and depression. It is often difficult, if not impossible, to distinguish the boundaries among these common illnesses. Is cognitive decline a symptom of a vascular change, a sign of plaques and tangles in the brain, or a symptom of loneliness after the loss of a spouse?

While co-morbidity of both physical and mental illnesses will be the norm as people age, their families will also have their own cluster of unique charac-

teristics. Families will vary in their bonds, expectations, and the resources they bring to the challenge of caring for elderly family members. In spite of the variation in elderly health problems and family context, families will be expected to care for their ageing members regardless of how long they live. As an elderly member ages, he will become increasingly dependent on his family for a variety of tasks that could include making critical health care decisions, allocating a portion of the family's resources for care, providing daily health care needs (e.g., giving an injection, bathing), and determining optimal living arrangements (e.g., home health or assisted living).

Social media have expanded the possibilities for family care across geographical boundaries. An Indian son in the United States may be talking on Skype to his ageing family member in New Delhi each morning. Regardless of the geographical distance, he may feel responsible to assess his elderly parent's wellbeing and to decide when he needs to intervene, including traveling to India to provide more hands-on care. An elderly, isolated family member's only link with the outside world may be her daily online conversation with a child who lives an ocean away. An adult child who straddles two cultures may have to navigate different norms (family care versus institutional care or aggressive medical care at all costs versus acceptance of death) and give up the hope of having a personal vacation because his vacation days are used to travel to see his ageing family member.

## Depression in Later Life

The combination of extended years of shifting roles in families as the elderly live longer and grow increasingly dependent on their adult children and the multiplying demands on caregivers suggests that both elderly family members and caregivers will be at increased risk for depression and anxiety. How depression and anxiety manifest themselves will vary greatly by culture. In some cultures, the elderly may be prompted by their primary care physicians to complete a depression inventory such as the PHQ 9, and the physician may explain depression as the source of the elderly patient's weight loss and poor sleep. In another culture, a depressed elderly individual may seek a traditional healer to cure his worsening symptoms. In some cultures, depressed elderly individuals may seek help from both providers of western medicine and traditional healers. An elderly family member of an immigrant family in the west may decide to move home to die or to receive affordable care such as an inexpensive, in-home caregiver. These geographic upheavals can add to the stress and depression that ageing families already face.

The family members who care for these patients are often as much at risk for depression as their elderly relatives. The caregivers, commonly women who also work outside the home, may devote 4-8 hours of unpaid care per day (1,2). A caregiver may dread the "demands" brought about by the ageing of the elderly family member and resent the drain on resources (e.g., financial, time, energy) that caring entails. These demands not only increase depressive symptoms, but they also increase susceptibility to other health problems (2). Even if elderly members remain vibrant and independent for longer periods than the elderly have in the past, they may still eventually face years of declining health and increased dependency. Thus, ageing children who face their own challenges may simultaneously be caring for their increasingly dependent parents. Even if an ageing family member is placed in assisted living, the emotional impact of caregiving persists.

## Psychosocial Treatment of the Elderly

Due to the prevalence of older adults receiving treatment for depression in primary care settings and the evidence that demonstrates the effectiveness of collaborative care (3), several primary care-based research initiatives have emerged to treat depression in the elderly. Two of these initiatives, which are described below, emphasize an integrated model of treatment.

**IMPACT** – A primary care physician and depression care manager (nurse, social worker, psychologist, family therapist) implement a shared treatment plan and consult with a psychiatrist as needed. The care manager provides education about depression, provides problem-solving therapy, and monitors depressive symptoms. A study of 1,801 patients showed that IMPACT significantly reduces depressive symptoms in comparison to usual care, and change persists after one year (4).

**PROSPECT** – To prevent suicide among older primary care patients by reducing suicidal ideation and depression, primary care physicians are trained to recognize depression and suicidal ideation in older patients. In addition, mental health specialists are included on the treatment team. PROSPECT studies show that patients who receive this intervention had decreased severity of depression and are less likely to report suicidal ideation (5). A study also found that patients participating in this intervention had lower mortality rates (6).

Collaboration among health care professionals shows very promising results for reducing depression in later life. Unfortunately, these initiatives have focused solely on the elderly patient, not on her family. An example from the United States helps communicate the important role of families.

As the baby boom generation enters old age and lives longer than any previous generation, Americans face a crisis: Who will care for ageing Americans, and how will that care be paid for? Jennifer Wolff at Johns Hopkins University quotes a Congressional Budget Office report that says, “The value of donated care probably exceeds that of any other category of long term care financing but is difficult to quantify in dollar terms” (p. 1529) (7, 8). Wolff goes on to note the many barriers to supporting families in the United States, such as legal barriers that exclude family members from both knowledge and decision-making capacity about their loved ones.

Despite families’ confused roles in health care, Wolff suggests that families now serve “as the backbone of medical and long-term care delivery” (p. 1530) (7). She also suggests that families’ contributions must be measured and documented before they can be valued. She offers specific suggestions on ways to include families:

Health information should be made available to family members according to patients’ expressed wishes.

Important aspects of family functioning that influence caregiving should routinely be documented in the medical record.

Screening of family caregivers at risk for burnout should be part of routine care.

Family members’ presence and identity at a patient’s health care encounter should be documented, and different perspectives on the problem should also be included in the patient’s documentation.

Family members often struggle with fear about how to be caregivers and feel guilt about not being able to do more for their loved one as they balance multiple responsibilities. Current legal and operational barriers exacerbate these emotions for families because they limit family members’ access to information that would help them better understand their loved one’s condition and more effectively function as caregivers. When a patient leaves the physician’s office or the hospital, his care often becomes the primary responsibility of family members.

In an effort to address these issues, the United Hospital Fund has implemented a programme called Transitions in Care-Quality Improvement Collaborative (TIC-QuIC), which completed its first round intervention in 2011 (9). The goal was to improve transitions for chronically- or seriously-ill patients between settings by providing training for family caregivers. The results showed that caregivers reported better preparation, and staff reported a decrease in their post-discharge workload. The TIC-QuIC project is one example of the powerful benefits of including family members on the health-care team.

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# *FACT SHEET: Taking Care of You*

# **SELF-CARE FOR FAMILY CAREGIVERS**



[www.caregiver.org](http://www.caregiver.org)

## **First, Care for Yourself**

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.

## **Effects of Caregiving on Health and Well Being**

We hear this often: “My husband is the person with Alzheimer’s, but now I’m the one in the hospital!” Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and wellbeing. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 percent higher than that of people your age who are not caregivers. The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and wellbeing at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than non-caregivers to practice preventive healthcare and self-care behaviour. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- sleep deprivation
- poor eating habits
- failure to exercise
- failure to stay in bed when ill
- postponement of or failure to make medical appointments for themselves

Family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco and other drugs. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Caregivers are more likely to have a chronic illness than are non-caregivers, namely high cholesterol, high blood pressure and a tendency to be overweight. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

## Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well-being and to get your own needs met.

## Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, “What good will I be to the person I care for if I become ill? If I die? Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example:

- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help?
- Do you feel you have to prove that you are worthy of the care recipient’s affection? Do you do too much as a result?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- I am responsible for my parent’s health.
- If I don’t do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.
- Our family always takes care of their own.
- I promised my father I would always take care of my mother.

“I never do anything right,” or “There’s no way I could find the time to exercise” are examples of negative self-talk, another possible barrier that can cause unnecessary anxiety. Instead, try positive

statements: “I’m good at giving John a bath.” “I can exercise for 15 minutes a day.” Remember, your mind believes what you tell it.

Because we base our behaviour on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. The result is feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

## Moving Forward

Once you’ve started to identify any personal barriers to good self-care, you can begin to change your behaviour, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.

### *Tool #1: Reducing Personal Stress*

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it—whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.

Your level of stress is influenced by many factors, including the following:

- Whether your caregiving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predicts how you will cope

now. Identify your current coping strengths so that you can build on them.

- Your caregiving situation. Some caregiving situations are more stressful than others. For example, caring for a person with dementia is often more stressful than caring for someone with a physical limitation.
- Whether or not support is available.

### Steps to Managing Stress

Recognize warning signs early. These might include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.

Identify sources of stress. Ask yourself, "What is causing stress for me?" Sources of stress might be that you have too much to do, family disagreements, feelings of inadequacy, or the inability to say no.

Identify what you can and cannot change. Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, "What do I have some control over? What can I change?" Even a small change can make a big difference. The challenge we face as caregivers is well expressed in the following words modified from the original Serenity Prayer (attributed to American Theologian, Reinhold Niebuhr):

"God grant me the serenity to accept the things I cannot change, courage to change the things I can, and (the) wisdom to know the difference."

Take action. Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation or having coffee with a friend. Identify some stress reducers that work for you.

## Tool #2: Setting Goals

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals you might set:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing and preparing meals.
- Engage in activities that will make you feel more healthy.

Goals are generally too big to work on all at once. We are more likely to reach a goal if we break it down into smaller action steps. Once you've set a goal, ask yourself, "What steps do I take to reach my goal?" Make an action plan by deciding which step you will take first, and when. Then get started!

**Example** (*Goal and Action Steps*):

**Goal:** Feel more healthy.

**Possible action steps:** Make an appointment for a physical check-up. Take a half-hour break once during the week. Walk three times a week for 10 minutes.

## Tool #3: Seeking Solutions

Seeking solutions to difficult situations is, of course, one of the most important tools in caregiving. Once you've identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one, giving you more confidence in your abilities.

## Steps for Seeking Solutions

Identify the problem. Look at the situation with an open mind. The real problem might not be what first comes to mind. For example, you think that the problem is simply that you are tired all the time, when the more basic difficulty is your belief that “no one can care for John like I can.” The problem? Thinking that you have to do everything yourself.

List possible solutions. One idea is to try a different perspective: “Even though someone else provides help to John in a different way than I do, it can be just as good.” Ask a friend to help. Call local resources and ask about agencies in your area that could help provide care.

Select one solution from the list. Then try it!

Evaluate the results. Ask yourself how well your choice worked.

Try a second solution. If your first idea didn’t work, select another. But don’t give up on the first; sometimes an idea just needs fine tuning.

Use other resources. Ask friends, family members and professionals for suggestions. If nothing seems to help, accept that the problem may not be solvable now. You can revisit it at another time.

Note: All too often, we jump from step one to step seven and then feel defeated and stuck. Concentrate on keeping an open mind while listing and experimenting with possible solutions.

## *Tool #4: Communicating Constructively*

Being able to communicate constructively is one of a caregiver’s most important tools. When you communicate in ways that are clear, assertive and constructive, you will be heard and get the help and support you need. The box below shows basic guidelines for good communication.

## Communication Guidelines

Use “I” messages rather than “you” messages. Saying “I feel angry” rather than “You made me angry” enables you to express your feelings without blaming others or causing them to become defensive. Respect the rights and feelings of others. Do not say something that will violate another person’s rights or intentionally hurt the person’s feelings. Recognize that the other person has the right to express feelings.

Be clear and specific. Speak directly to the person. Don’t hint or hope the person will guess what you need. Other people are not mind readers. When you speak directly about what you need or feel, you are taking the risk that the other person might disagree or say no to your request, but that action also shows respect for the other person’s opinion. When both parties speak directly, the chances of reaching understanding are greater.

Be a good listener. Listening is the most important aspect of communication.

## *Tool #5: Asking For and Accepting Help*

When people have asked if they can be of help to you, how often have you replied, “Thank you, but I’m fine.” Many caregivers don’t know how to marshal the goodwill of others and are reluctant to ask for help. You may not wish to “burden” others or admit that you can’t handle everything yourself.

Be prepared with a mental list of ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help. And they do want to help. It is up to you to tell them how.

Help can come from community resources, fam-



ily, friends and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength.

### **Tips on How to Ask**

Consider the person's special abilities and interests. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.

Resist asking the same person repeatedly. Do you keep asking the same person because she has trouble saying no?

Pick the best time to make a request. Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time. Prepare a list of things that need doing. The list might include errands, yard work, or a visit with your loved one. Let the "helper" choose what she would like to do.

Be prepared for hesitance or refusal. It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because he doesn't want to upset you. To the person who seems hesitant, simply say, "Why don't you think about it." Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.

Avoid weakening your request. "It's only a thought, but would you consider staying with Grandma while I went to church?" This request sounds like it's not very important to you. Use "I" statements to make specific requests: "I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?"

## *Tool #6:*

### *Talking to the Physician*

In addition to taking on the household chores, shopping, transportation, and personal care, 37 percent of caregivers also administer medications, injections, and medical treatment to the person for whom they care. Some 77 percent of those caregivers report the need to ask for advice about the medications and medical treatments. The person they usually turn to is their physician.

But while caregivers will discuss their loved one's care with the physician, caregivers seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient and the caregiver is crucial. The responsibility of this partnership ideally is shared between you as the caregiver, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone's needs are met—including your own.

#### **Tips on Communicating with Your Physician**

Prepare questions ahead of time. Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or the general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care. The physician only sees a moment in time with the patient. Make sure you let him/her know what your concerns are in their daily care/health.

Enlist the help of the nurse. Many caregiving questions relate more to nursing than to medicine. In particular, the nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.

Make sure your appointment meets your needs. For example, the first appointment in the morning or after lunch and the last appointment in the day are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.

Call ahead. Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.

Take someone with you. A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.

Use assertive communication and “I” messages.

Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear “I” statements like the following: “I need to know more about the diagnosis; I will feel better prepared for the future if I know what’s in store for me.” Or “I am feeling rundown. I’d like to make an appointment for myself and my husband next week.” Or “I need a way for my mother to sleep at night as I am now exhausted being up every two hours at night with her.”

### *Tool #7:*

### *Starting to Exercise*

You may be reluctant to start exercising, even though you’ve heard it’s one of the healthiest things you can do. Perhaps you think that physical exercise might harm you or that it is only for people who are young and able to do things like jogging. For-

tunately, research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking and gardening. Even household chores can improve your health. The key is to increase your physical activity by exercising and using your own muscle power.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time. Find activities you enjoy.

Walking, one of the best and easiest exercises is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension. Walking 20 minutes a day, three times a week, is very beneficial. If you can’t get away for that long, try to walk for as long as you can on however many days you can. Put walking into your life. Walk around the mall, to the store or a nearby park. Walk around the block with a friend.

### *Tool #8:*

### *Learning from Our Emotions*

It is a strength to recognize when your emotions are controlling you (instead of you controlling your emotions). Our emotions are messages to which we need to listen. They exist for a reason. However negative or painful, our feelings are useful tools for understanding what is happening to us. Even feelings such as guilt, anger and resentment contain important messages. Learn from them, then take appropriate action.

For example, when you cannot enjoy activities you previously enjoyed, and your emotional pain overshadows all pleasure, it is time to seek treatment for depression—especially if you are having thoughts of suicide. Speaking with your physician is the first step.

Caregiving often involves a range of emotions. Some feelings are more comfortable than others. When you find that your emotions are intense, they might mean the following:

- That you need to make a change in your caregiving situation.
- That you are grieving a loss.
- That you are experiencing increased stress.
- That you need to be assertive and ask for what you need.

### **Summing Up**

Remember, it is not selfish to focus on your own needs and desires when you are a caregiver—it's an important part of the job. You are responsible for your own self-care. Focus on the following self-care practices:

- Learn and use stress-reduction techniques, e.g. meditation, prayer, yoga, Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly, if only for 10 minutes at a time.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, taking a warm bath.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor, friend, or pastor.
- Identify and acknowledge your feelings, you have a right to ALL of them.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

# Caregivers of Older Adults:

# CHALLENGES AND SUPPORT

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“As the population ages the role of the family carer will become more significant and so a concern for their well-being and provision of appropriate support is of importance...“(Aggar 2010)

Informal caregivers, usually family members and friends, are now more than ever recognised as playing a crucial role in the provision of community aged care (Carr, Kimberley & Mercieca 2013). In the Australian Productivity Commission’s report, *Caring for Older Australians*, informal carers are identified as the major source of direct care for older adults, play an integral role in coordinating formal care services, and are essential to the functioning of the aged care system (Productivity Commission 2011b). This article will consider some of the challenges and support needs of unpaid family/friends as caregivers (carers) for older adults. Carers of all ages are affected by their caregiving role; discussion in this article includes its impact on older adults as carers.

Carer stress and burden is now a well-established aspect of the caregiving experience (Cummins et al. 2007; Deekin et al. 2003; Edwards et al. 2008; House of Representatives Standing Committee on Family, Community, Housing and Youth 2009; Savage & Bailey 2004; Schofield et al. 1998; Schultz et al. 2003). Each caregiver relationship is different and some carers may be better equipped to deal with the challenges of caring for a relative than others. Braithwaite (1990) observes “it is not necessarily the physical demands made on carers that define the burden of care, but rather the ‘psychological deficits

of caring’ and the ‘crises of decline’—degeneration, unpredictability, time constraints, the care relationship and a lack of choice.”

Australian researchers I.D. Cameron, C. Aggar, A.L. Robinson and S. E. Kurrle (2011) found that although many carers find aspects of the caring role satisfying, the effect of their caring responsibilities can lead to a decline in their own physical and mental health—especially when caring for those with dementia. They report caregivers are adversely affected in their employment and education prospects, financial position, and ability to participate in social and community life. (Chappell & Dujela 2008). Their research highlights the importance of identifying and assessing the family members who have an informal caring role.

## **Identifying Carers of Older Adults**

Many carers do not identify with the terms caregiver (or carer) because they consider their caregiving role to be normal part of their family responsibilities. This is especially true for those from ethnic and indigenous communities. In most countries medical practitioners, especially family doctors, are well placed to identify family carer(s) of older adults, detect when the family carers are at risk of physical and mental health problems from their caregiving role, and provide follow-up or referral as appropriate (Guberman et al. 2003). The rights of carers should be recognised in policy and legislation, with carer policies focusing on benefits, services, employment, and with the provision of the right for carers to request an assessment of their support needs (Department of Health. Carers. 2011).

## Older Adults as Caregivers

In the Research Update: Time to care? Health of informal older carers and time spent on health related activities: an Australian survey 2010 found that many older carers (96.2%) had chronic illness themselves, and those with greater numbers of chronic illnesses were those who faced the greatest overall time demands. The top health decline was found in carers who devoted between 8.5 and 10 hours a day to personal and caring health-related activities. These carers spent more time on caring for others than on caring for their own health. High levels of caring responsibility were associated with poorer reported carer health. Carers of older adults are often caring for other family members as well.

Ageing carers often have specific health issues which need to be addressed, such as coping with their own major health issues, managing their own stress and the energy levels required to be an advocate on behalf of the care recipient (King et al. 2010). The emotional needs of carers – their stress, anxiety and depression – which is often compounded by grief – are related to what is happening to the person for whom they are caring. Additionally, older and frail carers can suffer from injuries and emotional and physical exhaustion in caring for their own frail aged partner. (Aggar, Ronaldson & Cameron 2012)

## Carer Wellbeing

Research on wellbeing indicates that carers generally have low levels of life satisfaction and wellbeing. In the Australian Unity Wellbeing Index survey of 2007, Cummins and Hughes observed that the findings for carers in relation to wellbeing were “the lowest value we have ever recorded for a large group of people” (Cummins & Hughes, 2007, pvii). Litwin (2007) comments that older people’s social networks are limited and this is especially the case when needs are greatest. In the Mental Health Council of Australia 2009 report *Adversity to Advocacy*, mental health carers found that one of the most debilitating aspects of being a carer is the sense of isolation and helplessness, facing their own deteriorating health without adequate access to the support they need.

## Assessment of Carers and Their Caregiving Situations

Evidence-based clinical practice guidelines suggest early and ongoing carer assessment with flexible provision of interventions according to carer preference and assessed need. Increased needs should be anticipated if there are major changes in health status of the care recipient or carer, or environmental changes for the carer. Support may still be needed for the carer after the care recipient moves to a residential care setting or after his or her death (Eurofamcare 2006; Family Caregiver Alliance 2002, 2006). Assessment of the carer and their individual needs, and of the caregiving situation, can improve the health and wellbeing of the carer and ensure the provision of timely and appropriate support services for the care recipients (Cameron et al.2011).

“The implications of research as well as the principles of good practice unequivocally support the premise that assessing caregivers is a necessary and essential part of working with older clients in virtually every setting” (Zarit 2010 quoted in Cameron et al. 2011).

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