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## HRT: To Take it or Not?

*This article will discuss menopause, the role of hormone replacement therapy and the issues which menopausal and postmenopausal women have to face.*

Firstly, I will define some terms so that there won't be any confusion about their meaning in this article.

*Menopause* is the permanent cessation of menstruation resulting from the loss of ovarian follicular activity. However, the term menopause is commonly used to refer to the time of the female *climacterium* during which many women can experience biological, endocrinological and clinical symptoms. During this time a woman's menstrual periods decline and cease and her oestrogen production gradually decreases and there are fluctuations in the circulating levels of hormones. For the purpose of this article I will use the term 'menopause' to refer to this time.

*Postmenopause* refers to the years following the date of the last menstrual bleed which cannot be determined until 12 months has passed without a menstrual period.

*Hormone replacement therapy (HRT)* is the general name for the various pharmaceutical combinations of oestrogen and progesterone used during and after climacterium or menopause.

### Menopause

Menopause is a time in a woman's life which generally occurs at around 50 years of age but there are many varia-

*"Werribee Mercy Hospital — where the community is both recipient and benefactor."*

tions with some women experiencing it far earlier, when it is called premature menopause, and some women later. Given that in developed countries the average life expectancy has increased, most women may live one third or more of their lives after menopause. Apart from the fact that menstruation will eventually stop for every woman,

*"the experience of menopause is different for everyone"*

the experience of menopause is different for everyone. Menopause is represented in many ways but the two I want to discuss and which I feel are responsible for the way in which women approach and then experience menopause, are the medical or biomedical,

## FEATURING

<i>HRT: To Take it or Not?</i>	1
<i>From the Director</i>	5
<i>Is Health Promotion Valuable?</i>	5
<i>The Ethical Challenges of Alzheimer Disease and Our Ageing Population</i>	8
<i>Is Relieving Distress for the Dying Euthanasia?</i>	11

and the sociological perspective.

## The Medical or Biomedical Approach

This approach sees menopause as a time of ovarian failure in that most symptoms experienced by women at mid-life can be attributed to a deficiency in oestrogen. These symptoms can include hot flushes, night sweats, a dry vagina, breast tenderness, insomnia, headaches, tiredness, mood swings, loss of libido, poor memory, anxiety/panic attacks, itchy skin, chest pain, palpitations, aches and pains, bladder symptoms and pain during sexual intercourse.<sup>1</sup> As each woman's experience of menopause is different, the number and severity of symptoms can also vary.

*“symptoms which if unrelieved may negatively affect their quality of life”*

Some women are troubled little if at all, while others may have symptoms which if unrelieved may negatively affect their quality of life as determined by them. Some of these symptoms can persist after menopause but do not cause serious morbidity. However, the decrease in circulating oestrogen in the body over time has been implicated in the following two, potentially lifethreatening conditions. Firstly, it may lead to an increased bone fracture risk due to osteoporosis, and secondly, it may increase the risk of cardiovascular disease.

Osteoporosis is when the structure of the bone weakens to such an extent that the risk of fracture greatly increases. While there are many other contributing factors, such as a family history or a sedentary lifestyle, a rapid decline in bone density around the time of menopause can accelerate the process of osteoporosis. This condition may mean that bones may fracture after only a little stress, and can occur almost spontaneously. Up until the age of 45 years, men are far more likely to die from a heart attack than women. However, death rates

are equal for men and women by the time they reach their late sixties. Falling oestrogen levels after menopause, and the suggested effect that this has on lipids, clotting factors and blood vessel walls have been implicated in the increased risk of cardiovascular disease for women. While low levels of oestrogen may contribute to increased risk of a heart attack it must be acknowledged that it is only one factor. Smoking, obesity, a high fat diet, lack of regular exercise, family history and the coexistence of other diseases are also risk factors.

A medical approach to women's mid-life sees menopause as a deficiency disease and one would have

*“sees menopause as a deficiency disease”*

to say that the orientation is towards treatment of the hormone depletion, either to alleviate present symptoms, or to prevent future morbidity and possible death. This of itself may not necessarily be a bad thing, but there is a danger that by highlighting a specific stage of life as being optimal health (that of the reproductive years), we risk pushing the ethical boundaries of what is 'normal' and extending the limits to which we should go to maintain this normality.

## Sociological or Alternative Approach

Menopause is the time in a woman's life when she is no longer naturally able to reproduce. It is part of the cycle of life. There are two major events in every woman's reproductive life. Firstly, there is menarche and secondly there is menopause. Both these times which are a mirror image of each other, are natural processes but this does not mean that their course is always uneventful. There is however much scientific and popular literature which has a tendency to portray menopause negatively, as a time of loss of control and loss of sexual appeal and, as a time of risk. Conclusions drawn from research into women's experi-

ence of menopause can vary greatly according to the population surveyed. Research done in the community rather than just amongst those women who attend clinics, has found that menopause is not associated with significant health problems for most women. In fact, it was found that a small number of women

*“has a tendency to portray menopause negatively”*

experienced no menopausal symptoms apart from cessation of menstruation; the majority of women have mild but manageable symptoms and only approximately 10% of women have symptoms which affect their quality of life.<sup>2</sup>

While menopause brings about many bodily changes and possible symptoms, the stage of life at which it occurs is also a time when women may be assessing themselves and their changing situations. They may be re-evaluating their family and work lives; their partnerships; their social networks; their goals and ideas of themselves; and their perceptions of how they are seen in society.<sup>3</sup> Not everything that happens to a woman and her body during mid-life can be attributed to menopause. Ageing and a changing environment are natural phenomena and the transition involves an adaptation to a new situation and changing capabilities. Recourse to replacing hormones artificially should not be seen as the only way to adapt to these changes. A non-medical approach, while acknowledging a role for the use of therapy seems to emphasise more natural methods and a healthy lifestyle.

## HRT

Hormone replacement therapy usually consists of two hormones — oestrogen and progesterone. The oestrogen component relieves many of the acute menopausal symptoms mentioned above and reportedly confers benefits to the heart and to the bones as a preventive therapy.

The progesterone component protects the endometrium (lining) of the uterus. There has also been some suggestion that HRT may be associated with a reduction in the incidence of colon cancer and of Alzheimer disease.<sup>4</sup>

There may be side effects of HRT which can include breast tenderness, nausea, headaches and leg cramps which are thought to be related to the oestrogen, and premenstrual tension like symptoms such as headaches, irregular bleeding, irritability and feelings of being bloated which are thought to be related to the progesterone. There has been anxiety about the use of HRT and the incidence of breast cancer. It has not yet been proven that HRT causes breast cancer. Little agreement has been reached through clinical trials but there does seem to be some evidence that the length of time on HRT may have an effect on the risk of breast cancer.<sup>5</sup> However, it has been suggested that the progression of breast cancer undetected at the time that a woman commences treatment, may be accelerated by HRT. It is essential, therefore, that women on HRT have regular breast checks and mammography in accordance with NHMRC guidelines.

HRT can be given in a variety of ways and the method should be chosen by consultation between the woman and her doctor. According

*“by consultation between the woman and her doctor”*

to the NHMRC ‘the appropriateness and correct dosage of HRT are a matter of trial and error, and may take some months to evaluate.’<sup>6</sup> Before a woman commences on HRT comprehensive information needs to be gathered such as a medical history which may indicate the existence of other diseases which are contraindications for the use of HRT, and a history of symptoms. Investigations, such as blood tests, breast and pelvic examinations, weight and height as well as blood pressure are also necessary before

commencing HRT. Once taking HRT a woman needs to be monitored closely, taking note of any side effects. Her menopausal symptoms (if this is the reason she is on HRT) need to be reviewed regularly.

How long a woman stays on HRT will probably depend on the reasons why she started therapy. If it was for symptom relief then it is probable that she may only stay on it until the symptoms resolve — the time may vary as some women take a few years to pass through menopause. However, to benefit from the long term effects of HRT as a preventive therapy for osteoporosis or cardiovascular disease a woman will need to remain on HRT for a longer period.

## History

The use of oestrogen replacement therapy for menopausal women became popularised in the 1960s although it was around before then. From the mid 1960s to the mid 1970s there was an increase in dispensed noncontraceptive oestrogens. However, in the mid 1970s there were reports of the increased risk of endometrial cancer with the use of oestrogen so there was a decrease in the use of HRT. By the 1980s it was discovered that this increased risk of endometrial cancer could be countered if progesterone was prescribed with oestrogen and so HRT usage began to increase again. From then until the present day HRT use has been on the steady increase.<sup>7</sup>

## How Should Information About HRT be Given?

For women to be able to make an informed choice about HRT the following issues need to be covered: an understanding of menopause, the dispelling of any myths, an exploration of any unrealistic expectations, an understanding of HRT and an anticipation of any anxieties. Apprehension about breast cancer should not be underestimated as it is a much feared disease. Most women

around the time of menopause will know someone who has, or has had, breast cancer and despite the fact that there is a far greater likelihood that they will have a serious fracture or a cardiovascular event in the future, the risk of breast cancer may seem more immediate and identifiable. It is therefore important that health professionals and those providing information give accurate data about objective risk even though the woman herself is the one who will assess her own subjective risk and what that means to her and her future.

## The Media and Other Sources

Women have many sources of information and menopause and HRT are often discussed in popular magazines and newspapers. The media should be ethically responsible and objective in supplying information. In a study conducted by Richards et al, women were asked to select from a list their sources of information about menopause — 38% of the women received their information from magazines, TV or newspapers; 28% from their doctor; 27% from their mother; 26% from books, 26% from friends; 18% from pamphlets; 12% from other family members; and 5% from other health professionals.<sup>8</sup>

## Making a Decision – There is No *One Right Option!*

Ultimately it is the individual woman’s decision as to whether or not she will take HRT, despite whether her doctor suggests that she do so for either relief of uncomfortable and distressing symptoms, or as a preventive measure because she is at increased risk of a cardiovascular event or of osteoporotic fractures. It is an extremely difficult decision to make. Conflict in decision making arises when there is difficulty in identifying the best alternatives in the circumstances, and where the outcomes are far from certain. This is especially true if HRT is taken

preventatively. It is easy to see the benefit when symptoms are distressing and they can be relieved. Protection from possible, but not certain disease in the future is the potential benefit but when the woman does not have any of the symptoms of these possible disease processes before she commences HRT, it is difficult for her to rationalise that benefit. The decision involves high stakes which are related to potential gains and losses and the woman will have to make value tradeoffs if she selects one course of action over another. She may have to cope with regret because of positive consequences from rejected options.

### HRT for Public Health and Disease Prevention

Demographic projections in the medical press and the mass media show an expected increase in the numbers of postmenopausal women in the future. This could suggest an increasing public health problem due to the anticipated growth in what are often seen as menopause related diseases. It may be seen as a problem because firstly, these diseases place heavy burdens on the health and quality of life of women, and secondly, the costs of treating these diseases will be enormous for society.<sup>9</sup> If HRT is an effective therapy then these problems may be addressed by using it widely. Universal HRT use however, may be unnecessary and over zealous. Current opinion seems to be that those women most at risk of osteoporosis and cardiovascular disease, determined by such indicators as past history, risk factors and bone density testing should be advised to take HRT as preventive therapy. This raises many questions including the following. How long should women use such therapy — ten years, twenty, thirty, or for the rest of their life? How long is long enough to be 'protected' from the effects of some diseases? When would we be reconciled that death from cardiovascular disease occurred at a fitting time? If we discover other therapies which post-

pone chronic diseases should we advocate their widespread use and public funding?

### Conclusion

HRT is an example of a therapy which can have immediate benefit in the relief of some of the distressing symptoms of menopause. It can also be used in the hope of preventing, or at least minimising the effect of some potentially life threatening diseases. However, the causes of these diseases are multifactorial and maintaining oestrogen levels should not be the only strategy used to minimise their incidence. According to Hemminki and Topo: 'In prevention of chronic diseases, strategies should be non-specific and applicable to the whole population, such as non-smoking campaigns and promotion of good diet and exercise; in large-scale prevention, methods to prevent one disease should not cause others (even though the overall balance would be positive) if alternative methods give benefit with less harm; chemical prevention (ie. drugs) should not be promoted by health services without firm, empirical evidence.'<sup>10</sup> Therefore, using these strategies perhaps HRT should not be recommended other than in cases of increased risk.

Menopause is a natural phase of life despite the following surprising quote from the British Medical Journal written in 1996: 'Some women believe that the menopause is a natural event and that taking medication

**“menopause doesn't  
necessarily have to be viewed  
negatively”**

(hormones) should be avoided. These women are wrong: oestrogen deficiency is the unnatural state.'<sup>11</sup> By accepting menopause as a natural life cycle event this doesn't mean that symptoms should go untreated but it does mean that menopause doesn't necessarily have to be viewed negatively, nor that the only desirable or ideal period of a woman's life is the reproductive age, with the optimal hormone levels.

We must be careful that the treatment and experience of menopause does not become purely the medicalisation of a natural process. How a woman experiences menopause is highly individual and whether or not she has HRT is a personal decision. There are many factors however, which can affect this experience.

### ENDNOTES

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*Deirdre Fetherstonhaugh*

## From the Director

Media reports indicate that some people would like to move on from cloning sheep and other animals to cloning human beings. In some countries there would not yet be any law to prevent this happening if private funding were available for it. It is to be hoped that the cloning of human beings will be banned by law in the whole of Australia. At present it is illegal only in Victoria, South Australia and Western Australia.

A cloned child would be deprived of a genetic mother and father and other family relationships since the genetic material of egg and sperm would not be used in the child's formation. This would be unnatural and contrary to the child's human dignity. Natural embryonic twinning is quite unlike cloning a human being which involves fusing a somatic cell nucleus (cell other than a gamete) with an egg whose nucleus has been removed. Natural identical twins do have a genetic father and mother. A cloned human child would be a human individual, a person, a subject and not an object, to be created or used as mere means for the benefit of others, e.g. as a source of tissue for transplantation for a sibling. It would also be unfair to place the unreal expectations of the social parents on a growing cloned child. This kind of social genetic engineering should not be tolerated.

Once formed, a cloned human embryo should be given the same unconditional respect that is due to an embryo formed by the fusion of two gametes. This means destructive experiments on cloned human embryos would be as unethical as destructive research on IVF human embryos

in a laboratory.

It might one day be possible to form a cloned human embryo by taking the nucleus of a somatic cell from a person with Parkinson's disease and fusing it with an enucleated egg. In due time this cloned embryo could develop to the stage at which embryonic stem (ES) cells could be obtained and cultured. These could be induced to develop into new nerve cells which could then be transplanted to restore the damaged nerve tissues that cause Parkinson's disease in the donor. These new nerve cells would not be susceptible to immune rejection because they would be genetically the same as the recipient's cells. This sort of cloning technology would be an enormous advance for the treatment of a host of degenerative diseases.

This therapy, however, would have the serious ethical difficulty of destroying a human embryo to obtain the ES cells. If, however, these ES cells could be obtained by a method that did not involve destroying a human embryo, no offence would be involved against human life. This is the challenge for scientists — to find a way to use cloning technology for medical purposes with due respect for human life.

On behalf of the Centre's Board and staff I wish all our readers God's blessings for a happy Christmas and New Year.

Norman Ford SDB

## Is Health Promotion Valuable?

*Health promotion has become an important part of improving the health of the population. This article looks at the possible motivations behind the health promotion movement and the ethical methods of changing unhealthy behaviours.*

### Public Health

Public health focuses on the overall health of the population rather than on the health of specific individual patients. It is monitored using epidemiological data. This information can be used to establish which disease and illnesses are causing the public the greatest problem. The data is also essential to determine whether public health programs are successful. Public health programs have existed for some time and it appears that they can be credited with

improvements in the health of populations. For example, there has been a continuing decline in the death rate from cardiovascular disease, which is associated with improved blood pressure among the population and a fall in smoking rates.<sup>1</sup> Improvements in health are also the result of improvements in waste management, sewerage, water supply, and nutrition. The focus of programs aimed at improving public health is to protect populations from health hazards, prevent disease and illness and to promote practices that hopefully en-

courage individuals and communities to become healthier.

In order for public health to be effec-

***“public health must focus on background environmental and sociocultural conditions”***

tive it must focus some attention on background environmental and sociocultural conditions because these also, determine the health of an individual. Personal behaviour is only one determinant of health status, a determinant that an individual can

control and as such should be considered as important. Callahan suggests that ‘... public health problems — whether smoking, obesity, lack of exercise, or sexually transmitted disease — combine many elements mediated by behaviour and encompass social forces.’<sup>2</sup> These may be outside the control of public health agencies. In other words, public health programs need to aim at influencing personal behaviour, for which the individual is responsible, in order to improve the health of the population in general. It is also important to note that the primary responsibility for one’s health rests with the individual, not on the community.<sup>3</sup> Individuals should seek to preserve and maintain their own health as much as possible.

### What is Health Promotion?

The concept of health promotion has evolved in recent years to address lifestyle, economic, social and environmental factors as well as organic determinants of health. It can be defined as: ‘Multifaceted health education strategies which encompass organisational, political, community and economic interventions designed to bring about change in factors which determine, improve and maintain health.’<sup>4</sup> Health promotion strategies include individual and group education, social marketing techniques and other environmental, legislative and organisational interventions. The theory behind health promotion acknowledges that behavioural change requires an improvement in knowledge, beliefs, attitudes and skills as well as social, economic and legal support. Improvements in population health requires an adequate standard of basic living conditions; but they also require information on life skills, opportunities for making healthy choices, appropriate services and facilities, favourable social and cultural conditions and a total environment that enhances health. Health promotion strategies as much as possible should aim to have an inter-sectoral ap-

proach, that is, combine the resources of different government departments such as housing and employment along with those of health. Health promotion is just part of the government’s responsibility to provide health care and to improve the general health of the community.

### Reasons for Health Promotion

Tom Beauchamp suggests that we, as a community, have a right to be concerned about the social costs of voluntary health risking behaviours.<sup>5</sup> He claims that health promotion, or even restriction of behaviours which are hazardous to health, is only appropriate if a utilitarian cost benefit analysis reveals that controlling such behaviours would produce a net in-

*“health promotion should focus on improvements in people’s health status”*

crease in social utility. While this is certainly one criterion for deciding which unhealthy behaviours health promotion resources should focus on, it is probably too severe. I think that health promotion should focus on improvements, even simple measures, which will make a difference in people’s health status. For example, the overall social cost of people’s poor diets may not yet be too dramatic. Preventing these harms from occurring is very important. However, it can be predicted that as a result of poor diet cardiovascular disease and non-insulin diabetes will increase. Current health promotion does encourage people to eat reasonably low fat diets to avoid the onset of such diseases later in life. Encouraging better eating patterns may or may not produce a net increase in social utility but I think it is a valuable health promotion initiative even if it prevents the onset of only a few instances of disease.

Several other motivations for health promotion have been suggested. Having morally questionable motives might change the ethical

evaluation of a health promotion program so it is important to examine the reasons behind the health promotion initiatives. One reason suggested by Daniel Wikler is that health promotion is a form of paternalism.<sup>6</sup> Paternalism in the sense that some people, for their own good, need the government to impose (or perhaps encourage) healthy habits. There has been much debate surrounding the value of paternalism, especially when an individual’s autonomy has become so respected. However, I think paternalism, in the form of concern for the health of the population, might still be an ethically appropriate approach. This seems particularly valid when the alternative is for governments to stand by and do nothing, with the knowledge that individuals could do something to change their own behaviour and improve their own health status. If this was the case then governments might be responsible for failing to prevent the onset of some diseases.

*“a decrease in behaviours which are hazardous to individuals’ health is needed”*

A further reason sometimes raised as a motivation behind government support of lifestyle change is that a decrease in behaviours which are hazardous to individuals’ health is needed to maintain the effectiveness of the health care system. In other words, if everyone took risks with their health and became ill as a result, any currently viable healthcare system would collapse under the enormous pressure that widespread illness would place on it. Health care resources are finite, so any health care system based on the limitless availability of health care would definitely fail. This is not an appealing motivation for promoting healthy living but it might actually be what motivates some governments to participate in health promotion programs. Whatever the motivation behind health promotion campaigns they do play an important role in reducing illness and improving the health of the population.

## Coercion

Health promotion campaigns that involve placing an outright ban on unhealthy habits would probably be considered coercive and, as a result morally unacceptable. An example of such extreme measures would be banning the legal sale of products like tobacco and cholesterol rich foods. Coercive measures like these are unlikely to be accepted by any democratic liberal government. Perhaps, not because such measures are unduly coercive, but because large numbers of voters partake in unhealthy behaviours such as these. The persuasive and manipulative measures that governments may be more inclined to introduce are also the ones that are more difficult to evaluate. For example, a campaign against smoking sponsored by the government may be considered manipulative or even persuasive but it does not appear to impact on an individual's liberty. These types of campaigns are the ones that our community currently accepts.

## Taxation

A form of health promotion sometimes used involves taxation. Increasing taxes on unhealthy products or behaviours has long been suggested as a persuasive measure aimed at decreasing the use or consumption of hazardous products. One concern sometimes raised is that increasing the price of hazardous products might be another form of coercion. I think that for taxation to be considered a coercive measure, hazardous goods would have to be remarkably more expensive than they are currently. For example, cigarettes would have to be made too expensive for all but the rich. This probably would be coercion because some people could no longer smoke even if they wanted to.

*“taxation on products which are hazardous to health”*

If taxation is introduced, or increased, on products which are hazardous to health then many argue

that the revenue raised should be put back into the health care system. This money could either be used to cover the health care costs which are the result of the health damaging behaviour in question or, they could be used to encourage people to discontinue their health damaging behaviour. An effective example of the latter situation is VicHealth. VicHealth is a health promotion agency that ‘pioneers innovative health promotion strategies using a percentage of the tobacco tax to fund programs, research and sponsorship.’<sup>7</sup> Their programs aim to improve health in organisations, communities and individuals.

## Health Promotion Organisations

The central question for health promotion planners is always what works; that is, which methods or combinations are likely to prove most effective in addressing a particular health problem in a particular situation and for a particular target population. Answering these questions has provided some of the most controversial health promotion campaigns. Currently, in Victoria we have some graphic advertising campaigns aimed at reducing particular health risking behaviours. For example, we have the Traffic Accident Commission (TAC) commercials. These commercials readily warn us of the hazards of driving without wearing a seat belt, or whilst under the influence of alcohol, or whilst tired as well as a variety of other risky situations. They are considered to be effective because they display the real and horrible consequences of not driving safely. The Anti-Cancer Council has also tried to encourage people to limit their exposure to the sun by using graphic commercials showing a skin graft that was necessary as a result of skin cancer. This method of health promotion may seem dramatic but, the message that individuals should be taking measures to prevent disease has to be communicated, and showing them the risk they are taking is

possibly the most effective way. Other health promotion campaigns involve more subtle methods of be-

*“health promotion campaigns involve subtle methods of behaviour change”*

haviour change. Such an example is ‘Active for Life’ which encourages Victorians to participate in regular moderate physical activity. The key message is ‘Just find 30 minutes of moderate physical activity a day to be Active for Life.’ The message is conveyed when Active for Life sponsor such events as fun runs and bike rides. Other health promotion agencies concentrate on the prevention or control of a particular disease or illness. These agencies include: the Asthma Foundation, the International Diabetes Institute, the Australian Drug Foundation, Quit, SunSmart and the National Heart Foundation.

## Health Promotion Planning

Adequate health promotion programs should analyse health problems using epidemiological data and social research. Research should also be conducted on the potential reduction of inequalities in health status. Each health problem should be assessed in terms of its seriousness, urgency, severity and costs. If an epidemic is posing an immediate threat it should take priority over the initiation of programs to reduce a long term problem. Once public health problems have been identified research should be conducted on possible effective strategies. This research should include what action is currently underway to address the problem, is additional support likely to create an improvement or are other more effective strategies possible. After a health problem is identified and a health promotion program initiated further research should be conducted to ensure the program's effectiveness. The collection of epidemiological data is often the most effective way of measuring the success of health pro-

motion initiatives. For example, the mortality rates from colorectal have declined by about one per cent per annum since 1987.<sup>8</sup> This decline is the result of a combination of several factors including a reduction in disease risk through improved diet (less fat, more cereals and vegetables) and improved clinical management.

## Conclusion

There is, and has been for some time, a great resistance to the idea of public health which emphasises the health of the collective rather than the individual and that individuals can change their behaviours to influence their health status. This resistance remains in the face of empirical evidence that supports both concepts. Anti-smoking campaigns in Australia and many other countries,

including America, have been very successful. As I mentioned, Australian data indicates that there has been a continuing decline in the death rate from cardiovascular disease which is associated with a fall in smoking rates. There have also been declines in death rates from lung cancer in males. This evidence supports the idea that health promotion programs can reduce death rates, especially from diseases which are influenced by personal behaviours that are open to change. Health promotion initiatives should continually be encouraged so the incidence of many other diseases can also be reduced.

### ENDNOTES

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Tracey Phelan

# The Ethical Challenges of Alzheimer Disease and Our Ageing Population

*As our society ages we are going to come face to face with the dilemma of increasing numbers of sufferers of age-related dementias. In this article I examine some of the ethical problems that need to be addressed. I conclude that first and foremost a person must be respected for who they are, not what they can do.*

## Introduction

In the West the incidence of those suffering age-related dementia, the most recognisable of which is Alzheimer Disease (AD), is growing. Over 90% of AD cases occur after the age of 65 and its incidence doubles every ten years so that it occurs in nearly half of all people aged 85 years and older.<sup>1</sup> Because our ageing population is constantly growing older, AD and other age-related dementias will become increasingly prevalent in the future.

AD is a slowly progressive, degenerative disorder of the brain that eventually results in abnormal brain function and death. Initially there is minimal memory loss and a difficulty in finding the right words to use during casual conversation. The ability to perform simple tasks be-

gins to disappear. Cary Henderson, a history professor in the United States diagnosed with AD at age 55, described the difficulty and frustration he felt when trying to open a can of dog food. "The best I could do was to try to dig a hole, make a little perforation and see if I could extend the side of it — and it was something like a panic. I'm too clumsy because of the Alzheimer's."<sup>2</sup> As AD spreads through the cerebral cortex it begins to take away language ability and sufferers have difficulty naming objects or maintaining conversation. Eventually the disease progresses to the point where all ability to function normally is lost, all sense of self seems to vanish, and the sufferer becomes completely dependent on others for care.<sup>3</sup> The stages of AD can occur over different time periods for different individuals, ranging from 18 months to 20 years. The average

length is thought to be between 4 to 8 years, with sufferers eventually dying of diseases such as pneumonia.<sup>4</sup>

## Predictive and Diagnostic Testing

There are two kinds of tests available for AD. Predictive testing is available, in limited situations, in order to give a person an estimate of whether they may, at some stage in the future, develop AD. Predictive testing can be undertaken before there are any signs of symptoms of AD. Diagnostic testing, on the other hand, is undertaken on a person who appears to have the symptoms of AD in order to confirm whether or not they are suffering from it.

It has long been recognised that having a family member with AD dramatically increases the chances of developing the disease.<sup>5</sup> What is not

so clear is whether there is any advantage in having predictive pre-symptomatic testing. Ethical opinion is divided, not least because AD seems to be caused by a number of factors, both genetic and environmental, that interact differently in different people.<sup>6</sup> Predictive genetic testing *is* possible for those families

***“having a family member with AD dramatically increases the chances of developing the disease”***

with a history of early-onset AD (pre-65), although there are some familial early-onset AD cases that cannot be traced to any known genes.<sup>7</sup> The question of whether AD should be tested for is similar to the question of whether or not to test for Huntington’s disease. It should be left up to the individuals concerned. Genetic testing for late-onset AD is more problematic however, particularly if the testing is undertaken long before any signs of symptoms. Test-

***“testing for late-onset AD is not an accurate prediction of whether an individual will develop AD during their life”***

ing for late-onset AD only allows for prediction of a range of statistical risk and is not an accurate prediction of whether an individual will develop AD during their life. As pointed out by Post et al, ‘unnecessary anxiety would be the major concern’, not least because someone given a risk factor may ‘falsely attribute normal forgetfulness to the onset of AD and may make significant life-altering decisions based on such misinterpretation of risk.’<sup>8</sup> Given such possibilities, it would seem unnecessary and pointless to offer such testing, even for those individuals with a family history of late-onset AD.

Everyone dreads a diagnosis of AD. It’s effect on the lives of patients and their families can be devastating and both the patient and family experience grief. It is important that health care professionals understand

the responses of patients and caregivers and are able to help them develop a perspective to deal with it. Diagnostic testing for AD, after the appearance of early symptoms of forgetfulness, thus ushers in its own set of problems. According to Connell and Gallant, some families find that a positive diagnosis of AD provides a sense of relief. It means that disturbing behaviours can be attributed to a disease process that is beyond the sufferer’s control, community support can be accessed and plans made for the future.<sup>9</sup> Other families, however, find that they are now facing difficult emotional and practical problems ‘because they are no longer able to deny the symptoms.’<sup>10</sup>

Surprisingly, given that as a society we place a high priority on a patient’s right to know, a British survey of family members accompanying patients with AD found that 83% did not want the patient informed of their diagnosis.<sup>11</sup> The rationale for this appears to be a desire not to distress the patient over something that nothing can be done about. According to Meyers however, ‘communication through “patient led” discussions would diminish any adverse emotional effects of sharing painful diagnostic information.’<sup>12</sup> I agree with Meyers’ argument that diagnostic information, when handled sensitively, would allow patients to participate in important decision-making for the future.<sup>13</sup>

## **Long-Term Care**

Beyond predictive and diagnostic testing for AD is the long-term problem of caring for the AD sufferer in a way that still maintains their essential dignity. In the words of Post, ‘among the several most urgent questions of our time is whether human beings have in place the moral and ethical signposts that can point toward a future in which those that are forgetful will be treated with dignity.’<sup>14</sup>

Do we reduce the moral significance of those with dementia? Post cogently argues that our society, ‘for

which the image of human fulfil-

***“our society has diminished the importance of dementia sufferers”***

ment is framed by cognition and productivity’, has diminished the importance, indeed the very humanity, of dementia sufferers (Post 42). I would suggest that this is the same societal attitude that leads parents down the path of pre-natal testing in the fear of having a Downs Syndrome baby. Increasingly, we seem to be moving towards becoming a society that only values those who are able to contribute.

Post postulates an alternative that values ‘creativity as much as knowledge’ and sees ‘worth in the lives of people with dementia, simply on the

***“an appreciation of the redeeming words, “I am””***

basis of their continuing capacity for creative even if irrational events’ (Post 42). He suggests that we move towards an ethics of ‘personhood’ that seeks to include rather than exclude the vulnerable, and urges that rather than stick to the maxim ‘I think therefore I am’ we move towards an appreciation of the ‘redeeming words, “I am”’ (Post 18).

## **Discourse Ethics**

In order to examine this problem we need to be concerned with the experiences of those with dementia, and their carers, beyond the simple question of to whom, when and how to reveal a diagnosis of AD. Post suggests an emphasis on the theory of ‘Discourse Ethics’, also known as narrative ethics. The concept behind discourse ethics is to allow ‘the process of dialogue with those who have dementia and their caregivers to define what aspects of the illness are important’ (Post 17). I would also add that it is only in hearing the stories of those with dementia, and those who love them, that we can truly begin to appreciate the reality behind what often seem to be empty

philosophical norms. Discourse ethics encourages a continual search for a means of communicating with people with dementia 'in the hope of drawing on their remaining capacities' (Post 25).

McNeil offers a number of ways in which this can be achieved. She suggests that the person suffering from AD should feel safe in their environment as often what may have been comfortable and familiar becomes unrecognisable and frightening. Emphasis should be placed on maintaining current abilities, particularly those affecting dignity, rather than trying to teach new skills. Changes in environment and daily routine should be kept to an absolute minimum, routines should be simplified and choices reduced in order to minimise feelings of anxiety and frustration.<sup>15</sup>

Post gives particular praise to the recent development of Special Care Units (SCUs), 'one of the best examples of moral creativity in dementia care' (Post 25). SCUs operate on the principle that those who suffer from dementia often have residual strengths and they seek to find and encourage those strengths. Thus he gives an example of a man who could remember a boyhood task of carrying wood and whose self-esteem and emotional state were improved when he was encouraged to walk around carrying some kindling in his hand.

## Caregivers

One of the major problems facing society in the future, as the incidence of AD increases, is the increasing burden on family caregivers. Many caregivers, often elderly spouses or daughters with young families of their own, find they suffer increased anxiety, stress and depression.<sup>16</sup> On the other hand, as Post argues, the moral role of the family is vital as it is in families that an AD sufferer can still be truly found worthy of life (Post 54). Post recognises the problem facing these

families when difficult choices must be made in caring for both the young and the old, but reaches no conclusions, limiting himself to saying that

***"caregivers, often elderly spouses or daughters with young families of their own"***

'we must not be overly rigid in this area of ethics' (Post 54).

## End of Life

Sufferers of AD eventually reach a point where they are completely unable to care for themselves. Many of them refuse sustenance. The question that then arises is how far should we take medical care in this instance. Do we do all we can to keep them alive? Or do we measure quantity versus quality of life? I would argue that medical decisions that impose burdens on those with dementia should be avoided. Bearing in mind that most dementia sufferers are nearing the end of their life, life-extending treatments should be avoided where they will impose significant or intolerable burdens. Like Post, however, I am uneasy with the cultural norms that are leading to an acceptance of assisted suicide and euthanasia. Instead, I would advocate for what Post calls an ethics of hope.

## Ethics of Hope

An ethics of hope, rather than assuming that a diagnosis of AD means the end of a functional, rational life, would see the life left as still being important. As suggested earlier, it means valuing a person for their continuing capacity for creativity. It means that we respect the per-

***"respect the person for who they are, not for what they can do"***

son for who they are, not for what they can do.

The final word in this 'ethics of hope' comes from a sufferer in the early stages of AD. 'Then one day as I fumbled around the kitchen to

prepare a pot of coffee, something caught my eye through the window. It had snowed and I had truly forgotten what a beautiful sight a soft, gentle snowfall could be... As I bent down to gather a mass of those radiantly white flakes it seemed I could do nothing but marvel at their beauty. Later I realised that God granted me the ability to see a snowfall through the same innocent eyes of the child. I am still here, I thought, and there will be wonders to be held in each new day; they are just different now' (Post 19).

## ENDNOTES

- 1 Marcelle Morrison-Bogorad et al., "Alzheimer Disease Research Comes of Age," *Journal of the American Medical Association (JAMA)* 277 (1997), 837.
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- 12 Meyers, *Telling Patients*, 321.
- 13 Meyers, *Telling Patients*, 321.
- 14 Stephen G. Post. *The Moral Challenge of Alzheimer Disease*. (Baltimore MD: The John Hopkins University Press, 1995), 1. NB: All other references to this text will be contained in parentheses within the text.
- 15 McNeil. (No page numbers).
- 16 Connell and Gallant, *Spouse*, 1008.✚

Anna Stokes

# Is Relieving Distress for the Dying Euthanasia?

*The Victorian media have reported claims that the sedation of the terminally ill is the equivalent of slow euthanasia and the hastening of foreseen death in these cases is tantamount to intending death. This article clarifies some of the ethical issues involved.*

## Current Best Practice

A time comes when healthcare professionals, after discussions with their patients, may, and/or should, cease life prolonging medical treatment in favour of initiating palliative care in the best interests of their patients.

Comfort is the priority in the care of the dying. For those in pain, analgesics are given initially in low doses and then gradually increased according to need. Contrary to prevailing myths, Professor David Kissane points out: 'With a gradual increase in dose over time, morphine is also safe and large doses at times may be required for effective pain relief.'<sup>1</sup> He also says sedatives are used in cases of fear, anxiety, breathlessness and insomnia: 'Sedatives are typically given in small doses equivalent to five milligrams of Valium. Such

***“with a gradual increase in dose over time, morphine is safe”***

doses do not shorten life.'<sup>2</sup> Some dying patients moan and cry out as they experience a form of delirium called *terminal restlessness* which 'includes both involuntary muscle twitching or jerking, and relatively co-ordinated, semipurposive movements such as "fidgeting" or "tossing and turning"'.<sup>3</sup> Confusion may be evident in their thoughts. Sometimes there may be a reversible cause for this condition and it ought to be treated, e.g. urinary infection or dehydration. However, treatment of reversible factors alone may not provide relief for this distress of the terminally ill, and sedation may be indicated. Effective and safe drugs for the management of terminal restlessness include long acting clonazepam and diazepam and short acting midazolam.<sup>4</sup>

The dying who are distressed may be asked if they wish to be more sleepy for some hours. They may then be sedated, allowing periods of time for personal encounters and meals. It is important that they feel cared for and loved by family members and carers and that they do not feel they are a burden.<sup>5</sup>

## Terminal Sedation

Dr Rodney Syme, a urologist and President of the Voluntary Euthanasia Society of Australia, says: 'Pharmacological oblivion is the deliberate administration of sedatives and analgesics to the point of unconsciousness, maintained till death occurs. It is not an uncommon palliative care approach to deal with the intense pain or suffering of those for whom no other acceptable relief is available.'<sup>6</sup> The usual medical term to describe this is 'terminal sedation'. In his view it contributed to the death of one of his patients but a forensic pathologist found 'death was due to natural causes.'<sup>7</sup> Referring to terminal sedation Kissane says: 'A specialist palliative care practitioner may invoke the doctrine of double effect (relief of symptoms with the possible outcome of shortened life) in relation to sedation approximately once a year, at a rate of one per 300 deaths.'<sup>8</sup>

It is not known for certain whether such sedation shortens life, but this cannot be assumed to be the case. Practitioners, however, are aware of this possibility. But if a massive overdose is given, death would be hastened. The more routine use of low dose sedatives allows the patient to awaken and does not induce 'oblivion'.

## Respect Due to Human Life

Here I take for granted that human

life is inviolable and that it is immoral to *directly* intend to terminate, or unnecessarily endanger, the life of an innocent human being. Traditionally, moralists have distinguished between the *direct willing* of harm and the *indirect willing or permitting* of harm when it is the unintended but foreseen side-effect of an action (or omission) which one directly wills for its own sake, or for its foreseen consequences. These distinctions are used in the *Principle or Doctrine of the Double Effect* to solve some difficult medical ethical dilemmas. In short, it means that one may ethically perform an action from which both a good and a harmful effect follow, provided the good is not obtained by means of the harmful effect, the harm is not directly intended and there are proportionately grave reasons for allowing the harmful effect to occur. The moral worth of a person is not eroded by indirectly willing or permitting harm for proportionate reasons, but it is tainted by directly *intending* evil.

## Ethical Aspects of Relief of Pain or Distress

It is necessary to understand precisely what is meant by euthanasia. It is 'an action or omission which of itself and by intention causes death, with the

***“it is ethical to administer medically appropriate doses of sedatives and analgesics to prevent a patient suffering”***

purpose of eliminating all suffering.'<sup>9</sup> While the motive is pain relief, the intention to cause death by a lethal act is essential for euthanasia. In rare cases of pain or distress that cannot be adequately alleviated, and always with the competent patient's informed consent, it is ethical to administer medically appropriate doses of sedatives and analgesics to prevent a pa-

tient suffering, even though consciousness may be decreased for a while or there is a risk that life may be shortened. This can be justified by the principle of *double effect* provided the intention and dose are therapeutic, and not lethal for the patient. In extreme cases of pain or distress, it would be ethically permissible to completely sedate a dying patient until natural death occurred, provided normal nursing care continued.<sup>10</sup> This would not be a case of *slow euthanasia*.

The fact that death soon follows in both cases is not ethically relevant. What is crucial is the kind of action performed and the intention of the doctor. Administering drugs for pain relief is not the same kind of action as causing death. The misguided intention of giving a patient a lethal dose must not be confused with the compassionate motive of relieving pain. I admit that a doctor could confuse intending death with foreseeing the likelihood of death. A test of inten-

tion is that if a patient awakens and is symptom free, there is no need to re-

***“there is a world of difference  
between alleviating distress  
and killing the patient”***

administer further medication. Furthermore, some regard the sedating of a dying patient to prevent pain and distress knowing it could possibly shorten life as ethically the same as intending death. I believe this is a misreading of the situation. When one performs life saving surgery, the intention is to treat a patient, even though one foresees it might not succeed and result in the patient's death. This could hardly be described as intending to bring about death. In both cases doctors agree to permit the risk of death, but it would not be intended.

### Conclusion

There is a world of difference between alleviating distress and killing the patient. It is ethical to give relief

for pain and/or distress to the dying, even if in an extreme case, it could shorten life, provided one does not intend to kill. The law should recognise this as good medical practice. If this needs to be clarified in law, it should be done. But the intentional killing of innocent people is unethical and should not be legally deemed a proper part of medical practice.

### ENDNOTES

- 1 *The Age* Newspaper, 4 November 1998.
- 2 *Ibid.*
- 3 Alexandra L Burke, 'Palliative care: an update on "terminal restlessness".' *Medical Journal of Australia* 166(1) (1997), 39.
- 4 *Ibid.* 40-41.
- 5 Dr Sheila Cassidy, 'Care of the Dying,' *The Tablet* 3 April 1993.
- 6 *The Age* Newspaper, 2 November 1998.
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Norman Ford

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