Crisis: Young People Living in Aged Care Homes

Too many young people live in aged care nursing homes in Australia because there is a shortage of suitable alternatives. The Young People in Nursing Homes National Alliance confirms this, and advises that one young person is admitted into nursing home care every day.[1] Part two of this article will follow in the next issue of this Bulletin.

At March 2006 6,518 people under 65 years of age live in nursing homes across Australia.[2] This includes 1,565 people in Victoria, of which 223 people are in the 0 – 49 years age cohort.[3] The Committee Hansard, April 2005 reported that in Victoria the youngest nursing home resident was just nine years old.[4] Catastrophic injury, degenerative and neurological diseases, physical disability, psychiatric illness and intellectual disability are just a few of the conditions that either suddenly or progressively predispose a person under the age of 65 years to require ongoing nursing level care.   Winkler et al, 2006 surveyed 330 people <60 years who reside in nursing homes in Victoria.[5] Within this sample 37% had an acquired brain injury, 17% had multiple sclerosis, 15% had an intellectual disability and 7% had Huntington's disease. The remaining 24 % had a range of other disability types.[6]

The placement of young people with complex and chronic health needs in nursing home care is problematic on a number of different levels.

Complex support system

Confounding this target group time and again, the poor interface between the services offered by a diverse range of programs directly increases the likelihood of their entry into permanent nursing home care. The School of Social Work and Social Policy, La Trobe University states: '… the findings indicate that deficiencies in external support are more significant than the internal family variable (family environment or climate), in placement decisions.'[7] Young people with complex needs may require a range of services including rehabilitation services, acute hospital and medical treatments, home nursing services, attendant care, home help, aids and equipment, transport assistance, access support for leisure and recreation, supported education and employment.

In Victoria packages of individualised supports, group programs, equipment and a range of other services are provided through a number of Government Departments. This includes five divisions within the state Government Department of Human Services, and four Commonwealth Government Departments. What appears to result is a service system offered by the public and Non Government sector that is especially fragmented and complex. The Australian Federation of Disability Organisations advises that 'people with a disability find navigating the service system exhausting and frustrating. People are not offered flexible service and support options and are required to co-ordinate support from a range of different services.'[8]

A significant number of people have not been able to access the right combination of services in a timely manner to meet their needs. The plight of one such person, Peter, is described in MS Australia's (Victoria) August 2006 submission to the Senate Inquiry into the Commonwealth State/Territory Disability Act.[9] Peter, a gentleman who 'has had MS for 14 years', found it impossible to purchase a special pressure mattress to assist with his disability related skin care vulnerability, even though it was a pre-

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scribed treatment intervention.[10] The submission states the cost of the mattress was $7,650, and after the funding contribution of the Victorian Aids and Equipment Program Peter was 'unable to meet the $6,850 shortfall.'[11] The Australian Physiotherapy Association, responding to the same government inquiry state: 'Significant gaps in the availability and range of equipment exist and current schemes fall short in meeting demand and timely provision of appropriate equipment.'[12]

In theory, such small gaps in service ($7,650 for a mattress and a shortfall of attendant care whilst Peter is on a waiting list for Home First)[13] should be simple to rectify. When they go unaddressed, and when complications arise, the outcome is that people like Peter are at risk of entering residential care in a state of desperation and psychological trauma. The communication and negotiation between Government Departments that would have been instrumental in solving this problem obviously did not occur. This also raises the question of the responsibility of the wider community and local business sector in engaging such issues and helping to provide the solution. I wonder if corporate institutions, which foster a strong sense of civic responsibility, would become involved in the sponsorship of such equipment, if they were aware of the need.

Additionally, this problem further illuminates the difficulties encountered when people with complex needs experience multiple points of service entry, rather than what ideally should be an episode of continuous care. Take for example the fragmentation of service continuity experienced by Peter when seeking rehabilitation support in his home. The professional rehabilitation assessment is possibly worthless because the required equipment, purchased through yet another program is unobtainable.

The World Health Organisation imparts the wisdom that when '*unmet needs*' are ignored, the cost of the intervention in managing the ensuing 'crisis' 'leads to expensive and ineffective solutions.'[14] This practical logic is echoed by Blackwood, Manager Policy and Community Partnerships, MS Australia (Vic), whose experience demonstrates that in consideration of all the associated 'upstream costs', funding nursing home care for a young person with a disability is 'more expensive than providing the right care' in the first place.[15] The Young People in Nursing Homes National Alliance advises 'every year, $327 million is wasted by keeping the frail aged in hospitals because they can't access a nursing home bed…'[16]

Part of the solution

The Victorian State Government Disability Services Division is aware of the consumers need for increased flexibility and choice. Working towards this goal, Disability Services is in the midst of transition as it increases the availability of individual support packages.[17] The individual support packages provide individualised funding for people with a disability. There are currently between 1700 – 1800 people with a disability receiving individual support packages through the Support and Choice initiative launched by Disability Services in 2003/04.[18] I am advised that if the service is consistent with the individual plan goals, the consumer is free to purchase traditional disability, or other mainstream supports.[19]

Without planned intervention, this will not solve the limitations placed on clients due to inflexible program boundaries within the existing service system. But it should enable consumers considerably increased choice, as they are not obligated to purchase a service from a particular provider, as would be the case through traditional block funded programs. There are other caveats that warrant attention. People with a disability do not have the freedom to make changes to the supports that have been agreed to in their individual plan, without the authorisation of the Department of Human Services, even if the changes are still consistent with the goals of the plan.[20] The packages are also not available to all who need them. Disability Services advise there are currently 1,330 people identified on the Disability Support Register, who are waiting for the allocation of an individualised support package.[21]

On 10th February 2006 the Council of Australian Governments (COAG) announced the allocation of $1.1billion to support its 'Better Health for All Australians Initiative.'[22] Under this initiative, $244 million has been allocated to 'provide better care for younger people with disabilities in nursing homes.'[23] In Victoria, $60.2 million will be administered by the Department of Human Services, Disability Services Division through a program called *my future my choice*. This program has three objectives: to support young people in nursing homes to find appropriate alternative accommodation where possible, to provide better support for young people who remain in nursing home care, and 'to minimise future admissions [of younger people] into residential aged care.'[24]

This funding will make a significant contribution to address the crisis of young people in nursing homes. And yet with this tremendous opportunity abides commensurate responsibility. Will those authorised to implement government policy develop the required flexibility that will benefit the recipients of such funding? For example, will the systems be put in place to package the effective level of care required to meet the complex clinical needs of people wishing to reside in supported accommodation in the community?[25] Furthermore, will such flexibility become a feature of the service system to benefit those for whom the $60.2 million funding will not reach.? They are the people that were once younger people with disabilities admitted into aged residential care, who have been there so long, they are now between 50 and 65 years of age.

Inflexibility has been a characteristic of the ethical dilemmas embedded within the existing long term care arrangements for people with a profound level of disability. Ostensibly, the reach of the Victorian Disability Services Act currently does not cover some of the people who legitimately fall within the scope of its legislation.[26] It excludes people with a disability who reside in residential aged care, regardless of their needs and rights, because they have deferentially become recipients of Commonwealth Government funding. For example the Victorian State Disability Plan 2002 – 2012 goal 'to enable people with a disability to pursue their own individual lifestyles…'[27] is of limited practical meaning to young people in nursing homes. Finding themselves within the jurisdiction of the aged care sector, they have simply not been able to access Disability Services funding for community access supports to facilitate their own ease of access into the community.

For such people a sense of *community* presence is often restricted to the immediate environment of the aged care facility. Feelings of loneliness and isolation counterbalance the knowledge that they are in receipt of a valuable service -- admission to the aged care facility on compassionate grounds is a source of help, care and assistance that has not been available elsewhere. So it becomes a catch 22. Relief that the appropriate level of care is given, is entangled with an inner struggle that comes from the separation from family, friends and spontaneous involvement and interaction with the community, which of itself can be a form of grief and loss. We need to remember that it is the very accessibility of small and inconsequential choices we ourselves make every day, which in fact shapes and gives substance to the making of our own quality of life. Winkler et al's 2006 Victorian survey of '330 people under 60 years with high clinical needs residing in aged care facilities'[28] found that:

> This sample was extremely isolated from peers, with 44% receiving a visit from a friend less often than once per year. Sixteen per cent of residents participated in a recreation activity less than once per month and 21% went outside less than once per month. Of the sample, 34% almost never participated in any community-based activities such as shopping, leisure, visiting friends and family.[29]

More attention needs to be paid to the personal journey of the individual young person in residential aged care, especially in relation to important and normative lifestyle considerations. For example, what is the relationship between the residential location within an aged care complex and the attainment of community inclusion, familial membership, expectations for personal rehabilitation and therapeutic intervention? The evidence suggests that the linkages between young people in nursing homes and their satisfaction with these aspects of their lives tend to be poor.

The Young People in Nursing Homes National Alliance submission to a Government Inquiry, 2006 reveals: 'The inability to receive adequate long term care and support inevitably leads to deterioration in health and wellbeing.'[30] I imagine this is compounded by the young person's lack of connection with a peer group, increasing distance from the proximity of a community of choice, a lack of options for rehabilitation and therapies of choice and a sense of loss of control of personal direction. Such psychological suffering must surely impair or fracture any sense of personal identity and wellbeing. Winkler et al adds to this argument: ' Aged care facilities are not designed or adequately resourced to facilitate the active involvement of younger residents with high clinical needs in every day activities…[they] are at risk of occupational deprivation and the loss of their already limited abilities through lack of use.'[31]

Conclusion

Good governance of the long term care needs of disabled people requires urgent redress. Community and Government together, need to seek to understand the depth of the problem, implement appropriate solutions and proactively challenge the status quo, which is shameful. As Kendrick implores, 'it would seem quite pointless to seek to understand people if one is not going to do something with what one begins to understand. Insight alone, without action to support the person in their struggles for a better life themselves, would be voyeuristic and an indignity.[32]

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The Obesity Crisis

The causes of obesity are complex. Both our attitudes and lifestyles will need to change inorder to successfully address this issue.

Obesity has become a world wide epidemic with Australian obesity rates falling second only to the US. A report commissioned by Diabetes Australia found that the direct and indirect costs of obesity in 2005 were 21 billion dollars.[1] In Australia around 60% of women, 45% of men and 25% of children are overweight, with childhood obesity rates increasing by 70% since 1985.[2] The prevalence and steady increase of obesity related diabetes has been termed a diabesity epidemic and most worryingly is affecting even children and adolescents. Overweight and obesity are risk-factors not only in the development of diabetes but also some forms of cancer, cardiovascular disease and respiratory difficulties.[3] While it is clear that obesity is a serious cause for concern, due to its complexity it is not a simple issue to tackle. It is easy to place blame on the individual but the extent of overweight and obesity indicate that there are wide ranging factors in our society and lifestyles that need to be examined and addressed.

Risks associated with obesity

Overweight and obesity contributes to the development of cardiometabolic syndrome which is a major risk-factor for cardiovascular disease and chronic kidney disease.[4] [5] It is estimated that 379,000 Australians suffer from cardiovascular disease, stroke or hypertension due to obesity.[6] Other conditions that can occur include hypertension, skin problems, osteoarthritis, gall bladder disease, high cholesterol, respiratory difficulties including sleep apnoea, musculoskeletal problems, mental health and infertility. Obesity is associated with a small increased risk of cancer of the breast, colon, prostate, endometrium, kidney and gall bladder.

The term 'diabesity epidemic' refers to the parallel increases in the incidence of obesity and diabetes, not only in Australia but globally. It is thought that around 1.2 million Australians suffer from diabetes.[7] But what is most alarming about this trend is that cases of Type 2 diabetes in children and adolescents are being identified while previously this was unheard of. Diabetes is the 6th leading cause of death in Australia. Around 10-15% of Australians diagnosed with diabetes have Type 1 diabetes which occurs when the immune system mistakenly destroys the pancreatic cells that are responsible for producing insulin.[8] Type 2 diabetes affects 85-90% of Australians who have diabetes, and occurs when cells become resistant to the insulin that is being made in the pancreas.[9] [10] This results in a build up of glucose in the blood stream leading to the shrinking of blood vessels and arteries and also nerve damage. Type 2 diabetes has multiple risk factors. While some of these cannot be controlled, such as genetics, nationality and age, some of the major

risk factors such as lack of exercise, poor nutrition, high blood pressure and obesity can be managed.[11] Diabetes is a progressive disease that at present has no cure. The progression of Type 2 diabetes can be slowed by lifestyle modification before medication and insulin are required. In a 1999 AusDiabetes survey it was found that for every case of known diabetes there was one undiagnosed case, indicating that around half of people with diabetes are unaware that they suffer from the condition.[12] This leads to greater probability of suffering from the complications of diabetes such as blindness, stroke, heart and kidney disease, infection (leading to amputation) and nerve loss. It is estimated that in the year 2005, 102,204 Australians had diabetes due to obesity.[13]

Causes of obesity

Studies have shown a positive correlation between certain genes and genetic mutations with obesity, demonstrating that people with a particular genetic make-up are predisposed to overweight and obesity.[14] These studies highlight the complexity of obesity and demonstrate that it is indeed more difficult for some individuals to maintain a healthy weight. Recently it has also been shown that Type 2 diabetes also has a strong genetic component which makes certain individuals at a greater risk of developing this disease.[15]

In Australia we live in a highly obesogenic (obesity promoting) environment. We have easy access to cheap, energy dense foods. We also lead busy lives with little time for food preparation, exercise and proper rest. And to add to all of this our media sources constantly bombard us with advertisements of unhealthy foods.

An Australian study examining the influences on women's diets found that time and monetary constraints were perceived as barriers to eating a healthy diet.[16] It was found that women of low socioeconomic status cited the cost of healthy food and time constraints due to work commitments as barriers. There is a common perception that healthy food is more expensive. This may be true in rural regions but in metropolitan regions this is not the case. A program piloted in Western Australia aimed to teach people with low incomes how to improve their diets through better managing their food budgets.[17] By demonstrating that healthy food was generally cheaper when compared kilo for kilo and giving practical advice about budgeting and shopping there was an increase in fruit and vegetable consumption and participants developed more balanced diets. Certain junk foods are of greater concern than others. Soft drinks in particular are thought to have a significant impact on obesity as they have little effect on satiety, which is the feeling of fullness. Hence consumption of food is not proportionally decreased when soft drinks are consumed.[18] This is why the NSW and the Victorian governments are banning sugar sweetened drinks in schools.[19 20]

For children and adolescents, time spent watching television has been positively correlated with obesity.[21] It is thought that watching replaces other more active pastimes and is also combined with the consumption of junk foods. Additionally there is a lack of sporting and recreational facilities in lower socioeconomic areas. This makes it more difficult for all individuals to be involved in affordable sport and exercise. This is combined with the fact that parents and other individuals do not feel it is safe to use parks or walking paths. Public transport in outer suburbs is poor, leaving many people dependent on cars for longer distances thereby reducing the opportunity for incidental exercise. Long hours of work also make it difficult for people to spend time preparing healthy meals. Sleep deprivation is a common problem in our society and it can lead to a greater risk of obesity.[22] Inadequate sleep can lead to changes in hormone regulation leading to increased hunger levels and cravings for junk food.

An analysis of food advertising at nine supermarkets in Sydney found that 82% of all food promotions directed at children were for unhealthy foods with 75% of promotions using television and movie celebrities and cartoon characters.[23] This advertising may impact on children's food choices and may further contribute to the current obesogenic environment. Television advertising has also been implicated in the promotion of childhood obesity. When examining the extent of food advertising during children's television programs, fast food restaurants and confectionary were the most advertised food categories and were two and three times more likely to be shown during children's shows than adult television shows respectively.[24] This shows that advertising for unhealthy foods is targeting children.

Successful strategies

The British Economic and Social Research Council examined which strategies were effective in encouraging people to live healthier lives.[25] It was found that most successful strategies are positive, encourage people to set specific goals, teach positive self-talk and review progress. The 'Choose Health' program, devised by a research group at Melbourne's RMIT University, has been highly effective in helping adolescents achieve improvements in their body composition. The 'Choose Health' program involves teaching adolescents and their parents about making positive changes in eating and exercise habits but they are not given diets or exercise programs.[26] Results have shown that participants had reduced their body fat by six percent and watched less television.[27] The 'Choose Health' program highlights the need to encourage, provide support and teach individuals how to make positive, long lasting changes.

Ethical considerations

Parents have a direct bearing on their children's health. It is imperative that they prevent their children from becoming obese or at risk of developing Type 2 diabetes. Obesity is not only detrimental to a person's health but also their quality of life. Therefore parents must be provided with the relevant education that will enable them to teach their children healthy habits. If regular health assessments were carried out by schools or family doctors, parents could be informed as to whether their child's eating or exercising habits need to be changed.

Parents and their children can also be helped by ensuring that schools and the media promote a healthy lifestyle. It is unfair and unethical to subject children to advertisements of products that are harmful to their health as they do not have the capacity to critically analyse the messages they are receiving. It also makes it more difficult for parents to instil healthy habits in their children. The number of commercials for junk food during children's television viewing time could be severely restricted and be replaced by health promoting messages. Some have suggested that in the future junk food advertising should be as severely restricted as tobacco adverting such is the extent of the harm. Additionally children's cartoon characters could be used to advertise healthy foods. Encouraging healthy habits in older children and adolescents can be quite difficult. By restricting unhealthy foods in the school environment health messages from parents, governments and teachers would be reinforced.

While some foods are not as healthy as others, when eaten in small amounts they do not cause obesity. It would be unreasonable to ban all 'junk food' from supermarket shelves and take away stores. However if individuals changed their eating habits then businesses and manufacturers would be encouraged to produce healthier foods. Currently even foods that are advertised as being healthy e.g. low fat are often high in sugar or salt. This is misleading the consumer - therefore the way foods are labelled should be regulated better. This could be achieved by regulating the claims that can be made by manufacturers and by simplifying labels to indicate the percentage a given amount of fat, carbohydrate or salt corresponds to a recommended average daily intake for an adult and child.

State and national governments acknowledge that tackling overweight and obesity will take much time. Due to the complexity of this disease many aspects of our environment will have to be examined. It will be important to provide recreational facilities and safe parks and footpaths in all areas. Providing sufficient and safe public transport and recreational facilities would encourage people to do more exercise. Ensuring that all individuals have access to affordable healthy foods is of vital importance. Well advertised community based facilities and practical education programs designed to give everyone the opportunity to learn how to develop a healthy lifestyle is a necessity, not an optional extra.

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Mariam Ghosn ✠

Planning Future Health Care

This is an article to introduce readers to the issue of people planning their options for future health care and medical treatment, and the importance of taking it seriously and acting on it.

Most adults live their lives generally satisfied with their own health, only going to visit their general practitioner when they are hurt in an accident, catch the 'flu, a fever, feel unwell, or experience pains or some other symptoms that cause them concern. They want to be informed by their doctors about their present state of health, any medications they should take as well as any precautions they should take in the immediate future to prevent any eventual deterioration in their health. Valuing their own privacy, they tend to keep information about their health or medical condition to themselves without talking about it to others, especially those outside their family circle.

Ever since the disappearance of the extended family and the advent of the nuclear family in the last few generations, elderly people, many of them grandparents, find themselves living alone. Their adult children and grandchildren visit them, but seldom would conversations touch on what should happen to them if they were to become unwell. Talk about death or end of life health care or medical treatment decisions would hardly ever arise: it could be considered threatening to people living alone. This would not have been the case in times past when several generations lived in the same household or in close proximity to each other. The pall of a *death angst* seems has fallen over our Western society: it is no longer polite to mention issues related to dying in ordinary conversations. Talk of death is almost taboo. Has belief in enjoying eternal risen life in Christ disappeared?

The vast majority of people do not die suddenly after an accident or unexpected heart attack, but usually after a period of chronic illness. Once these patients become critically ill, many of them are not in a position to be involved in discussions about their future care nor to make decisions about their end of life treatment options. Doctors are frequently confronted with situations of having to make decisions about end of life care for incompetent patients about whom they have no indication of their preferred treatment options. In such situations doctors may be inclined to treat patients aggressively without knowing their wishes about treatment options or the cessation of active treatment in favour of commencing palliative care treatment. This could have the unwanted consequence of some patients being kept alive in conditions and circumstances wherein they may have to endure more suffering than they would have wished. It is possible this could in part be the result of the failure of timely discussions taking place between patients, their doctors and family members about preferred end of life treatment decisions. It is surely better not to leave doctors and family members in the unenviable quandary of not knowing patients' preferred options for care and/or medical treatment.

Need to plan future care

It is necessary to prevent having the kinds of care and treatments that people really would not want to be given when they are no longer able to make their own decisions or express their wishes. Planing future care is also needed out of respect for close family members who are left concerned and embarrassed by not having been made aware of their relative's wishes for future care and preferred treatment options. An obvious, laudable and worthwhile solution seems to be for people to start planning their future care in good time.

Discussions about one's future care could normally be initiated by patients' general practitioners or their specialists. The content of this discussion should, among other things, include education of patients about the current status of their illness along its pathway, what patients might expect in the future, and the likelihood of 'success' if new treatments were to be adopted. Basically, the content of these discussions would be similar to what should usually be done to obtain informed consent.

If this does not occur, people may rightly take the initiative at a certain point and talk to their general practitioners or specialists about their future care planning. It would not be wise for people to allow general practitioners or specialists, with whom trustworthy relationships have been developed over the years, to be left out of discussions about their future options for health care and medical treatment. These discussions offer an opportunity for patients to be involved in their future care at a time when rational discussions can be held with their respective doctors. Their planning should be regarded as an ongoing process and not as an event designed simply to produce some sort of final written document.

After a talk or two with their own doctors, it would be good if people shared their thoughts on their wishes about their future health care and medical treatment with important family members and/or close friends. It needs to be kept in mind that these discussions do not necessarily have to take place with family members if, say, someone has been out of contact with them for some time. It would be helpful if these issues were discussed with at least one close and trusted relative or friend. Many people may also wish to discuss their preferences with their minister of religion.

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After being informed by discussions with their doctors, family members and friends on all relevant matters, people's preferences for future health care or medical treatment options could be determined. They may also express their wishes concerning religious, spiritual and pastoral care issues at the end of life, with requests of a non-clinical nature, e.g., music therapy, funeral arrangements etc. It would then be helpful to have their wishes written down and to ensure they are made available to all who need to have access to them as required. Catholic Health Australia and the Committee for Doctrine and Morals of the Australian Catholic Bishops Conference have just published *A guide for people considering their future health care (The Guide)* which contains an useful example of *A model statement for future health care*.[1] Whatever is written should be shown to peoples' relevant healthcare professionals to be assured they have not omitted something that may become relevant for them in the future. However, a written document expressing wishes for health care and medical treatment options should not be considered something definitive as though it was a last will and testament. Indeed, there is no obligation to put one's personal future care plan in writing, although it would be wise to do so. In any case as peoples' circumstances change, so should their plans.

People's plans should be reviewed periodically after discussions with all the relevant persons if their circumstances are about to change, e.g. a move to a new suburb or a threatened financial set-back. It could well be that after reviewing their plans some people may realise that there is no need to change what they had previously decided and written. People's plans are likely to be influenced by the circumstances of the place where they live, whether it is at home, in a residential care facility or in a nursing home.

Appointing representatives

While written expressions of patients' wishes are helpful guides, it may not be necessary to follow them to the letter if patients' circumstances change. To make provision for this and other situations it would be useful for the elderly and hospital patients, while still competent, to appoint trusted and reliable relatives or friends who would be willing and available to act as their representatives, or even legally appointed agents, to make decisions on their behalf if they were to become incompetent – always in the light of their known wishes and treatment options. In Victoria, a competent patient aged 18 years or more can appoint an agent with enduring power of attorney under the *Medical Treatment Act* 1988 or an enduring guardian under the *Guardianship and Administration (Amendment) Act* 1999. If a patient appoints both and there is disagreement between them regarding medical treatment, the person responsible is the patient's medical enduring power of attorney appointed under the Medical Treatment Act 1988. Once a legal agent is appointed relatives should

be informed of this appointment. Representatives and legal agents, however, should discuss maters with close relatives of the patient and try to reach an agreed solution regarding continuing or discontinuing any medical treatment. This would greatly contribute to creating an atmosphere of peace and harmony as well as avoiding risks of legal action being taken in the courts if disputes were to persist.

Two important moral points on appointing their representatives are clearly made in *The Guide* and are addressed to patients:

> the guidance that you give should respect their moral responsibility to value and care for you until death intervenes. The person who accepts the role of representative takes on the same responsibility that each of us has to protect and sustain our own life.[2]

> Given the continuing debates over euthanasia and the withdrawal of medical treatment, it is important to state explicitly that you do want life-sustaining treatment that is reasonable to be provided unless it becomes futile or is overly burdensome.[3]

As Dr. Brian Pollard says medically futile treatment 'may be defined as treatment which has no recognised capacity to cure the illness, to restore function or to relieve distress adequately, now or in the future.'[4]

Planning future care in hospitals

The situation of people in an acute hospital setting is quite different from that of people at home, in residential age care facilities or in nursing homes. Once admitted, they become hospital patients and are placed under the care of their treating doctor(s) and other healthcare professionals. Competent patients should discuss their condition and general situation with their doctors in regard to medical treatment options. Only doctors should provide patients with information about their medical diagnosis, prognosis and treatment options. In agreement and liaison with patients' treating doctors, specially trained healthcare professionals may assist competent patients to understand the implications of their options and to decide on their preferences regarding their future health care and medical treatment that their doctors may have suggested. Where necessary, trained nursing staff could facilitate some competent patients to begin arrangements for the appointment of a suitable person as an agent with enduring power (medical) or as an enduring guardian and also to assist patients to ensure that their relatives are informed of their appointment. Specially trained staff could ensure that patients' planning and wishes for their future medical care are clear and available for all who need to see them. They could also ensure that plans are available within medical histories or notes, and are appropriately followed. Pamphlets and reading material on

planning options for future health care or medical treatment could also be made available in hospital wards.

Planning for end of life decisions

Planning future care and medical treatment for patients in need of chronic care in hospitals may, after their condition becomes critical, shift its general medical focus to end of life decisions. For incompetent patients, doctors need to discuss treatment options with patients' representatives or legal agents, and whilst bearing in mind patients' previously expressed wishes, they must make ethically responsible decisions for reasonable care and/or treatment in the circumstances with the guidance of patients' representatives or legal agents. It is important that patients' informed wishes, as far as reasonably possible, be followed in relation to the following: the use of *cardiopulmonary resuscitation* after cardiac arrest, the continuation of acute care or the beginning of palliative care, the continued use of mechanical ventilation, and the initiation or continuation of medically administered nutrition and hydration.

The following passages from *The Guide* offer sound advice to patients in this regard:

> It may be helpful to others for you to think about the circumstances in which you would regard some intrusive life-sustaining interventions (such as cardiopulmonary resuscitation, renal dialysis or mechanical ventilation) as overly burdensome.[5]

> If you have swallowing difficulties, tube feeding is appropriate if it nourishes you and/or alleviates your suffering, unless it would be overly burdensome.[6]

Benefits of planning future care

Planning peoples' future care is an ongoing process which shifts the focus away from the completion of documents towards facilitating discussions about their ethical values and their preferences for health care and medical treatment. This planning enables patients to take a more active role in the care they wish to receive in the future when they may not be in a position to communicate their wishes. In this way they would enjoy an improved perception of their quality of care. The experience of being treated as human persons with dignity is uplifting for people who are keenly aware of their vulnerability and fragility towards the end of life's journey.

Such planning would lead to an improved level of comfort for those appointed as representatives, legal enduring guardians or agents with enduring power of attorney (medical) with regard to their roles. Experience shows that patients who had appointed such representatives, enduring agents or guardians are far less likely to die in hospital whereas patients without such representatives, agents or guardians are far more likely to have been hospitalised in the last 6 months of their lives.

ENDNOTES
[1]Catholic Health Australia and the Committee for Doctrine and Morals of the Australian Catholic Bishops Conference, *A guide for people considering their future health care*, Canberra, 2006, 7.1. There is also a guide for health care professionals. Both publications can be obtained by using the order form under publications on *Catholic Health Australia*'s website: www.cha.org.au
[2] Ibid. 5.1.
[3] Ibid. 5.8
[4] Dr Brian Pollard, *The Principles of Palliative Care. An Introduction*, Sydney: published by Brian Pollard, 2002, 41.
[5] *The Guide*, 5.5
[6] Ibid. 5.7.

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Reflections on Society, Medicine and Death

Philosophers and followers of various faiths have long debated the meaning of life and death. Death's one constant is that it is everyone's last act. What is variable is how one views death. Whatever one's belief there are considerable efforts made to delay death, so much so, that in Western Society, in particular, a death is often viewed as a type of failure. There is so much emphasis on the importance of life and living up to our potential that we have deprived death of meaning and allowed this parting from life to be medicalised.

Exposing the modern death

The 'how do people die' question probably has an infinite number of connotations and therefore answers. This could be considered in terms of the biophysiological, the biopsychological and indeed the transcendental, spiritual, cultural and religious aspects. It may also be considered a subjective and therefore private matter related to whether a death is or isn't dignified from the point of view of those involved. Over time, nations appear to have become immune to certain aspects of death, yet extremely sensitive to others. For example, there is often extreme grief expressed at the death of the individual, even after they have lived a longer than average life-span, but only fleeting regret or outrage at the death of many through acts of nature, through famine, pandemic disease, warfare and

terrorism.

The why of a person dying raises similar questions as the 'how', but it certainly is often incomprehensible – such as death caused by wanton acts of violence, terrorism or warfare or beyond reasonable understanding, such as the death and destruction that nature can unleash. Whilst death may seem to serve no purpose and indeed contribute to hardship, it can sometimes bring benefits. Some of these are intangible, such as a sense of relief for the person who may have experienced great discomfort, or the rapid death of those with infections such as Ebola, which reduces the risk of exposure to those in neighbouring communities. But a common good may also be derived by the death of certain individuals in certain circumstances. Indeed, a study involving bereaved parents identified that sometimes death can bring value in that it can lead to altruistic acts such as organ donation, volunteer work, charitable fund raising, support group development and adoption.[1]

Where people die varies between developed and undeveloped societies. In developed societies, hospitals are institutions which provide medical and surgical treatment for persons ill or injured. They also seem to be the place where people go to die. This is not to suggest a cause and effect relationship, but more a sad indictment that some cultures don't do death well. Clark quotes findings that in the UK almost a quarter of occupied hospital bed days are taken up by patients who will die within a year with some 60% of all deaths occurring in hospital.[2]

Even in Australia people are more likely to die anywhere but in their own home, with one study suggesting that just under 16% of people with cancer die at home.[3] Which suggests that almost 80% of deaths, and surely many of the ones in private residence, are subordinated to some type of medical intervention - just by the fact that they are actually within some type of health care facility or the dying person is receiving some type of inpatient or even out-reach hospice or palliative care service.

The medicalisation of death

It is common knowledge that Australia has an ageing population which will have future implications for their care. What is not so commonly known is that recent experimental strategies have identified key genes and intracellular pathways that are responsible for ageing and longevity. Through animal studies, manipulation of some of this new knowledge may pave the way for people to not only live longer but have good health through old age.[4] On the other hand Callahan[5] states, 'the most fundamental problem with technological medicine is two-fold: that it can give us a longer life and a slower dying and that it can keep us alive when we might be better off dead'. Kelleher suggests that Australians have 'traditionally shied away from defining and expressing ideas about dying'

and 'perspectives on dying will be inadequate as long as they remain technical, clinical and institutional'.[6]

Medicine has been accused of hijacking what is natural, such as birth, and creating medical problems for available technology to fix. Can we blame medicine or should we scrutinise more closely society's love affair with the technological imperative. Did people come into the world, live and then die differently in the era before the rise of medicine? The dying process has been thoroughly examined from all imaginable aspects. The medicalisation of the dying process, unlike birth, has seemingly been more readily tolerated, possibly because, as a culture, we make extraordinary attempts to deny our mortality.

Clark is critical of the medicalisation of death but acknowledges that 'paradoxically, what we are seeing is the medicalisation of palliative care, a specialty that opens up a space somewhere between the hope of cure and the acceptance of death'.[7] Palliative care is thus another panacea, albeit a necessary one, thanks to medical knowledge. Nor need it mean that death is imminent. Indeed someone may be in receipt of some type of palliative care service for days, months or even years. Terminal care, on the other hand, means that someone will die in the very near future.

Who should decide when there are finite resources, and despite some people believing that the imperative of medicine is to keep them alive forever, there may be nowhere to go or no-one available to keep them alive. Why? Because the health care system is over-crowded with people who are actually in the process of dying but don't know it yet, or if they do they or their family deny it and do all in their power to delay it. Or is it fear of the unknown or fear of leaving the known that makes some people want to live at any cost. Whatever the reason, many people don't want to think about dying, or only about it as something that happens to other people.

Ethics of death

Porter and colleagues[8] suggest that some issues associated with death, such as euthanasia and the right to die, became prominent once advances in technology that sustain life became available. Indeed medical technology has confounded the very definition of death, especially when terminology such as 'beating heart cadaver' is used to describe someone who is considered to be brain dead, but whose life support is continued until their organs can be harvested for donation. To the casual observer, there appears to be no visual distinction between the 'live' person kept alive with life-support technology and the 'deceased' person whose 'body' is medically supported to retain the viability of potential donor organs. The 'dead-donor rule' can be perplexing for some and is not always easy to apply.[9] Modern technology has contributed to medicine in many ways including extending life by what may be con-

sidered unwarranted and expensive means. Is it any wonder that many people think that they have the right to live forever and that medical science will help them become immortal.

The maxim that nature takes care of its own is flawed otherwise humans would not be born so relatively helpless and in many ways revert to the same state when death is imminent. The ethics associated with the care of the dying person is caught up with legal rights such as the distinction between 'ending life care' which is not legal and end-of-life care which legally cannot be refused. Ethically and morally both arguments have been discussed extensively by academics and clerics yet, in many Western Societies, the distinctions have had to be decided by law.[10]

In bioethics there is no distinction between withholding and withdrawing life support technology, yet many feel the latter to be more morally suspect. For most Christians treatment with double-effect (palliation of symptoms at the cost of life) is permitted. Yet there is evidence that despite a patient showing physical signs of impending death, burdensome treatment is sometimes continued. A US study found that 51% of patients with dementia and 11% of patients with cancer received enteral tube feeding and died with the feeding tube still insitu.[11] Perhaps what should be scrutinised more closely is who should decide when treatment is withdrawn or withheld and how these decisions are made. Sometimes this is easy to answer, for example, a parent or a legally appointed guardian. Or more generally, a society that can afford to immunise their young against deadly viruses and those that cannot because they are too poor. Of course, the latter case seems unjust and global powers have done much to remediate this.

Ritual

Rituals are said to be cultural devices that facilitate the preservation of social order and provide ways to comprehend the complex and contradictory aspects of human existence. Funeral rituals are described as symbolic enactments that provide meaningful and affirming experiences for the bereaved.[12] There was a time when death was mostly surrounded by ritual, certainly in the Christian tradition. A person, after hopefully living a long and 'good' life, died in their own home surrounded by the same people, family or colleagues who surrounded them in their life. Indeed there was a certain serenity to the passing over of the spirit. The dying person was kept company by the living before they passed and then the living kept company and prayer with the deceased for a certain period of time. A period of mourning helped the bereaved accept the loss. It was accepted that the body was mortal but the soul immortal.

In the new millennium, many of the traditions associated with death seem to have been subjugated to efforts to delay the inevitably of death. In many ways the modern death is clinically prescribed and sanitised, with mourning hastened. Around the world end of life cultural practices vary according to belief and faith.[13] The spiritual nature of death has been explored extensively. Spirituality is considered a human characteristic. As Finnis states, 'So each of us has every level of being – the physical solidity and dynamisms of a star of a galaxy, the chemical and biological complexity and self-directedness of a zygote, a tree, or a lion, and then some more....' and that '… spiritual capacities subsist even when our bodily makeup is too immature, injured, or decayed to allow them to be actualised fully, or perhaps perceptibly at all. It is possession of these capacities that makes us each human and the equal of each other in basic dignity, worth, value, and so in human rights'.[14]

Dignity and Death

Fortunately the human side of end of life care hasn't been denied and palliative care appears to fill a gap between what was once traditional and what has become technological. Of course, no-one should have to have a painful death, nor should anyone fear that death need be painful. In this context medicalisation of the dying process has added a level of dignity to the dying process especially where there is associated discomfort. However, there is a lack of consensus about where in the continuum of a terminal illness, for example, that hope for a cure ends and expectations of impending death begins. Norten and Bowers found that 'decisions made near the end of life often have profound consequences'.[15]

A recent report suggests that about 80% of Australians know, often a year or more in advance, that death is coming.[16] Many would argue that in these circumstances at least people have some choice in the *management* of their death, when so many do not, due to violent unexpected death, or lack of access to modern health care. And there are those who may never know that they are dying since they die peacefully and normally at the age when their biological clock stops. Unexpected death, however, does take away the ability to complete unfinished business, say goodbye to loved ones, seek forgiveness, or receive what is commonly called 'the last rites'.

Catholics may receive a number of sacraments that together comprise the 'last rites'. The Sacrament of Reconciliation allows competent persons, who are sorry for their sins, to obtain God's forgiveness, and thereby find it easier to forgive and be reconciled, if necessary, with family members and others. The Sacrament of the Eucharist or Holy Communion, whereby the dying person receives the Body of Christ, the 'Bread of Life', for believers, is also commonly given as a last rite. The Sacrament of the 'Anointing of the Sick' strengthens and comforts them spiritually, whether or not they are dying. This sac-

rament gives God's forgiveness to penitent sinners, even for those deemed incompetent, provided they were sorry for their sins before becoming incompetent, e.g, lapsing into unconsciousness. Receiving this sacrament does not imply that there is the expectation that the recipient is about to die. Indeed it can be received as often as the believer needs it. For Christians death is not an end. As the Catholic liturgy for the dead says: 'Life is changed not ended'.[17]

The future of end-of-life care

There is evidence that the majority of those with terminal illnesses want to die at home[18] but as said earlier, most do not. Questions have been raised about what new models of end-of-life care would accommodate the large numbers of individuals who want to die in the comfort of their own home.[19] Planning future care enables patients to make decisions about their future health care in consultation with their health care providers, family members and other important people in their lives.

Perhaps the medicalisation of death has been useful in some respects especially for the person who will only accept the process of dying if they can consider it as a failure of medicine, and in doing so abrogate a control over their individual death, that they probably didn't have in the first place. But, as Michael Ashby and his colleagues so recently wrote, 'Appropriate care and decision-making at the end of life can only occur when death and the dying process are acknowledged, worked with, and regarded as an integral part of modern medicine'.[21]

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