‘Ethical Issues in the Care of the Aged’ — Report on a conference held at St Vincent’s Hospital Melbourne on 16 November 2001

Helen Monkivitch RSM (Director, Leadership Development Mercy Health & Aged Care) welcomed participants to the seminar. She announced a commitment to a Chair in Aged Care Nursing for July 2002 that is jointly funded by Mercy Health & Aged Care, the Sisters of Charity Health Service and Australian Catholic University. This commitment reflects the increasing importance of Aged Care in the community.

Norman Ford SDB
Director Caroline Chisholm Centre for Health Ethics

Overview on the Dignity of the Human Person

Ford spoke on the inviolable dignity and value of the human person, regardless of one’s age or state of health. He gave examples of how we experience our worth and explained how human nature, composed of body and a spiritual soul, make each human individual a person. Since his complete text appears in this Bulletin there is no need to say more here.

Mary Barry
CEO Victorian Association of Health & Extended Care

Responsibility, Accountability and Funding

Barry points out that the contribution of taxpayers towards the funding of the Aged care sector brings with it a level of responsibility and accountability. Approved Aged care providers are responsible to the Commonwealth government for:

- the quality of care they provide
- user rights for the people to whom care is provided
- accountability for that care, and
- if responsibilities are not met, sanctions may be imposed.

Various government departments have responsibilities. The Department of Health and Aged Care is responsible to the Minister, who is responsible to Parliament, which is in turn accountable to the citizens.
Accountability refers to certain obligations that arise within a relationship of responsibility for particular services such as the performance of duties and the acceptance of sanctions/redirection. This involves three components: who is to be held accountable, by whom and for what?

Over the last few years a process of accountability has arisen that is termed partisan/political accountability. This describes a political process where politicians hold a minister accountable where they can (achieved by tools such as question time, debates and so on). The media and the opposition also achieve it. Both bring pressure on those who have a recognised responsibility to justify their actions. While regulation and accountability, according to Barry are important, the increasing level and focus on accountability has led in her opinion to a loss of overall responsibility for the Aged Care sector.

Barry suggests the future of the Aged Care industry requires a balance between accountability and responsibility. In relation to responsibility, she argues there is a need for:

- Government to provide adequate funding to enable the sector to fulfil its responsibilities
- Responsible Government policy is required to address staff shortages, capital funding and so on
- Responsibility for best standards in technical know how
- New management practices
- Training and professional development of staff.

Barry argues that the industry must take responsibility for its future. The current multiple accountability system she says has contributed to a situation where staff suffers from low morale, fear and a lack of confidence. What is required is a mechanism of accountability that creates an atmosphere where staff members work creatively and seize responsibility for the continued improvement in the care of the frail aged. Barry finished on a high note of optimism, encouraging all who work in aged care to be proud of their professional work and involvement in the care of the aged.

Mary Lyttle
CEO Residential Care Rights

Code of Conduct and Ethical Practice

Lyttle introduced the new Australian Code of Ethics and Guide to Ethical Conduct for Residential Aged Care. The purpose of the Code is to identify shared human values for caring, to foster the well being of people receiving care, and to support the integrity of the professionals providing care. It is also a useful tool for providing an ethical response to difficult caring situations and can be used as a basis across the industry as a voluntary Code. The basic items of the Code that emphasise the rights of individuals are found on the first page, (eg, the right to privacy and confidentiality, the right of the individual to life, liberty and security). The implementation of the Code is found under the headings of guide to ethical conduct. This outlines the obligations and practices of the providers, family/representatives, employed and contracted staff, and attending professionals. The Code sits alongside the accountability framework and can be used as a basis for staff education, to provide information for consumers and families or simply as a checklist.

Richard Gray
Director
Aged Care Services

Employment Practice

Gray points out that it is the people who care for the aged that are the main asset of a healthcare provider. His ethical analysis of employment practices focuses on the Aged Care worker as a person with dignity and integrity. Respecting and caring for workers demands that they receive appropriate pay, good working conditions, affirmation, and opportunities for personal and career development. The working environment ought to be characterised by fun, warmth, mutuality, inclusiveness, equality and respect for the ethos and character of the residential care facility. Education in the ethos, spirituality, culture and ethics of the particular tradition of the healthcare provider is a necessary prerequisite of employment. Gray emphasises that no worker ought to participate in an activity that a person in conscience considers wrong and against their beliefs. He suggests a good test of ethical practice is what he calls “the newspaper front page headline test”. If you do not wish your actions to be open to public and open scrutiny then reconsider your decisions/actions.

Prof Rhonda Nay
Professor of Gerontic Nursing, La Trobe University

Autonomy and Duty of Care

Nay, believes passionately in the rights of older people, provided those rights do not harm others. She defines autonomy in terms of a person’s right to choice and risk taking. Her research in nursing homes has led her to conclude that nurses were depersonalising older people. Their misplaced kindness fostered a relationship of dependency, passivity and learned...
helplessness (Seligman) which resulted in poor life experiences for residents. Nay argues citing Hans Selye that some degree of stress is associated with risk taking which is essential to development and life. Examples of risk taking include crossing the road, driving a car, flying, abseiling and rock climbing. While some may die or receive injuries from these ventures, we do not deprive people of the right to drive or fly!

However, according to Nay, when older people are forced to live within the healthcare system, we want to eliminate all physical risk from their lives. Nay argues that this policy is frequently aimed at minimizing overt physical harm and protecting the back of the healthcare system. Furthermore, she argues that removing the right to take risks deprives older people of control and autonomy. She emphasises that the nurses’ duty of care is to the whole person in context. When care is reduced to thinking of the older person in their physical state, the duty of care is neglected. An example of this according to Nay is in the area of sexuality. Age and dementia, she argues, should not prevent individuals from enjoying a happy and fulfilled sex life. Often staff and families say that older people, especially those with dementia in residential care, should be protected from amorous advances. However, these views are often based on assumptions and are simply impositions. Nay asks if an elderly demented person wished to have an orgy on a nightly basis in their own home who is to “protect them”?. The duty of care she says involves informing the person of the risks involved, and getting to know the person and their needs. This involves listening to the person and their family. If an older person who is the focus of an amorous approach is angry, withdrawn and fearful, it is a clear indication that they are not choosing to have an “interaction”. On the other hand, she asks, if they are blissfully happy, who is being protected when the source of this bliss is removed? Finally, Nay argues that there is no life without stress and that we cannot eliminate risk without eliminating the person. She contends the overzealous risk management of the older person may protect a physical body from bruising but it may damage irreparably the already vulnerable soul!

John Brooks
CEO Aged Care Association of Victoria

Privacy, Confidentiality and Information

Brooks presented a short tour of pending legislation and the key elements of legislation that currently impact on providers and workers in residential Aged Care. He defined privacy in terms of seclusion, withdrawal from public view, securing of one’s private life or personal affairs.

The requirements of the Aged Care Act 1997 focus on 6 aspects; personal information (opinions, information in databases, ensuring that information is true and objective), protected information (personal details not disclosed willy-nilly, kept for strict and intended purposes), records principles (kind of records that are to be kept – appraisal accommodation details, medical records and so on), responsibilities of approved provider (criminal codes apply for non compliance), use and disclosure of information (requirements of accreditation standards), and maintenance of records (recorded, stored and maintained).

The Privacy Act 1988 has had a significant impact on care providers. There are 10 National Privacy Principles, which provide individuals with the rights to access, to complain and seek redress. The NPP’s are: collection of personal information, use and disclosure of information, quality of personal information, security of personal information, openness, access of individuals, identifiers, anonymity, trans-border data flows and collection of sensitive information. The NPP’s are underpinned by legislation but are subject to guidelines and organisations can develop guidelines and submit them for approval.

However, the Victorian state legislation (Health Records Act 2001) is not negotiable. Cost and inconvenience are not an excuse. Brooks strongly advises that workers and providers familiarise themselves with the legislation. He suggests that a systematic view of the legislation and cross-referencing all of the various legal obligations is necessary. He is convinced that most organisations have the capability to do this work using their own personnel. Finally, Brooks argues that parallel policies, practices and procedures need to be developed that will ensure privacy of information in relation to staff.

Susan Koch
Senior Lecturer, Gerontic Nursing, La Trobe University

Restraint

Koch defines restraint as “any physical, chemical, or environmental intervention used specifically to restrict the freedom of movement – or behaviour perceived by others to be anti-social – of a resident designated as receiving high or low care in an aged care facility”. She does not see restraint in terms of equipment used or as a medical intervention but in terms of intent and who decides. Koch contends that restraint in aged care deprives the individual of autonomy, and self-confidence and causes psychological
Koch challenges the assumption that restraint is supposed to eliminate the risk of injury. Hence, she calls for the normalisation of risk. She sees restraint as an infringement of the right of the individual to take risks. She suggests that nurses can be manipulative and only give particular information to get the decision they want! The individual who is restrained is also cut off from personal communication. Restraint may be justified on the basis that organisations don’t have enough staff. Hence, it is seen as cost effective!

Koch points out that restraint may lead to accidental strangulation, decreased muscle strength, orthostatic hypertension, impaired balance, increased susceptibility to falls and nerve injury. She suggests that if families were informed of these risks to their loved ones then they would be strongly opposed to restraint. She is passionate in her belief that a restraint free environment in aged care is possible. She believes that this will take time and tenacity.

Hudson challenges the assumption that end of life issues in long term care of the aged from the perspective of rights, duties and obligations. She does not believe that this approach is appropriate for those in the “fourth age” – the age of frailty and dependency. Hudson presents an alternative ethical school of thought that she considers is more appropriate, one that is concerned with the needs of care, respect and meaning. These human needs, she argues emerge as more pressing at a time when the condition of the elderly makes autonomy least attainable.

The ethical school of thought that Hudson advocates is termed virtue ethics/everyday ethics/communicative ethics. This approach is person centred and considers the individual in his/her relationships. The individual is viewed as interrelated and interdependent with others in community. As such, values, beliefs and practices that articulate dignity, quality and self-respect are clearly sign-posted. These qualities/virtues and values flourish when the individual is known and understood by others. This occurs in a relationship of listening, mutuality, trust, confidence, sensitivity and care. It is within such a personal relationship that questions of meaning can be explored at the end of life. Individuals may have unfulfilled dreams, wishes, fears and concerns. It is in the ordinary everyday experiences of the daily round of care (eg showering) that virtue ethics finds its basis. In this context, ethical decision making focuses on the narrative unity of the person’s life, rather than on isolated events. Hence, the choice of a particular treatment is based on whether it is beneficial or burdensome to this particular person. Hudson argues that she has presented an ethical framework that emphasises the elderly dying person as an active agent. In doing so, she challenges the stereotypical image of the passive dying person. In this way, she believes she has made a contribution towards understanding and personalising the experience of death. Finally, Hudson asks is each death recorded and acknowledged through symbolic action in the aged care community’s history or are others left wondering how meaningful will their lives be considered at the end?

Dr Rosalie Hudson
Aged Care Consultant

End of Life / Point of Death Issues

Hudson challenges the school of thought that considers end of life issues in long term care of the aged from the perspective of rights, duties and obligations. She does not believe that this approach is appropriate for those in the “fourth age” – the age of frailty and dependency. Hudson presents an alternative ethical school of thought that she considers is more appropriate, one that is concerned with the needs of care, respect and meaning. These human needs, she argues emerge as more pressing at a time when the condition of the elderly makes autonomy least attainable.

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Assoc Prof Sally Garratt
Caulfield Gerontic Medical Centre

Dementia, Depression, Suicide

Garratt pointed out that dementia is the major health problem facing older people today. 60-70% of aged care residents have cognitive problems related to a form of dementia and this figure is tipped to rise to 90%. However, only 7-8% of older people with early to moderate symptoms of dementia live in residential care. The majority reside in the community. Garratt emphasised that people who have dementia retain many personal strengths. She stressed that while people with dementia operate in their own reality, their personhood and “self” is very much alive and present. Families must be encouraged, she said to see their loved ones as persons and not things or objects.

Of particular concern to Garratt is the disproportionate amount of surveillance that is proposed for the elderly person with dementia. She asks “How would you like to be treated when you are 85 and living in a residential care”? She argues that people will require an environment where they are safe and where they have external space to move freely and have an acceptable level of risk. She is opposed to 24hr camera surveillance, microchips and bracelets being used to track down the individual as if he/she was a criminal.

Garratt notes that depression is the most neglected health problem of older people. There are numerous myths that indicate that it is somewhat normal for elderly people to be depressed. Garret challenges these myths. She says it is possible to lift the mood of people (maybe
they are “down” because of the shift from a 3 bedroom home to sharing with 30 others) by counselling, talking and brightening up the new environment. She acknowledges that alarm bells should ring when we see particular signs such as a loss of interest in things that individuals find pleasurable. Treatment such as medication can be offered. However, she cautions against confusing this with the need for precious time out to reflect quietly.

Garratt acknowledges suicide in older people is a serious issue and that it is not directly linked with dementia. The risk factors for suicide are multi-factorial and complex. Some of the risks include chronic pain, terminal illness, dementia, isolation, depression, and loss of spouse, loss of income and living alone. There are also many myths about suicide such as people who talk about it don’t do it. Garratt reminded us that most people aged over 75 are mentally stable and doing fine. Older people she says simply ask that they be taken for who they are and that they be given the regard that is their due.

Susan Koch
Senior Lecturer, Gerontic Nursing, La Trobe University

Abuse of the Elderly and of Care Staff

Koch presented a snapshot of a report on overcoming abuse of older people with dementia. The aim of the report was to identify and investigate the issue of elder abuse in relation to older people and their carers. It also investigated the awareness of this issue among service providers and the general public. Some of the issues covered in interviews and forums included what constitutes abuse, how it may be recognised, and the precipitators of abuse incidents. The major precipitators of abuse were identified as vulnerability, overwhelming perceptions of stress and feeling unsupported and lack of relevant knowledge and skills. Preventative strategies were considered to be a priority. Examples of strategies include educating the public in relation to enduring power of guardianship and powers of attorney. (For details of the report see www.alzvic.asn.au).

Jane Verity
Founder and Director Dementia Care Australia Pty Ltd

Physical Contact, Intimacy, Sexuality

Verity’s philosophy is that the “spark of life” can be rekindled and the lives of people with dementia and their carers truly enriched. The question of sexuality in the elderly is often swept under the carpet according to Verity. Stigmatisation with its assumptions characterises conversation about the sexual behaviour of the elderly. She wants carers to speak openly about this subject not in a clinical manner but with a heart full of love, warmth and respect. She emphasises that sexuality is a natural part of life no matter what age. Elderly people have the desire for sexual contact and expression. What changes in the elderly are not their sexual needs but the ability to have these needs fulfilled. Verity insists that carers must listen to the stories of people. This is one way of dealing with the issue of sexuality. Verity’s intention was to air the issues without pretending to give answers to the ethical problems raised.

However, she asks: How do we deal with people with dementia who have sexual urges? “How do we know if a person with dementia is giving consent to a sexual relationship?” and “How do we decide what is inappropriate sexual behaviour?” Some professionals, according to Verity, offer paternalistic advice such as introducing diversionary strategies to take peoples minds off sex. However, she notes that in Denmark some residential care facilities have made pornographic videos available for their clients. According to Verity the elderly absolutely enjoyed the “therapy”. As a result, she claims inappropriate sexual behaviour decreased.

Verity introduced two scenarios that raise ethical issues in the care of the aged.

Scenario one presents two people in aged care who have formed a sexual relationship. The lady is older than the man and has dementia. The man does not have dementia. Verity asks us to confront our assumptions about this relationship. She notes as soon as the diagnosis of dementia is formed, a process of labelling begins and the person and the relationship are stigmatised. Some of the assumptions are, according to Verity, that the person with dementia does not know what her needs are or how to fulfil them. And that this is an abusive relationship because the woman cannot give consent to sex. She asks, do you first enter into a sexual relationship by making a contract or when we talk about sexual urges, feelings and arousal. Is not this something that slowly happens?

Scenario 2 presents two people with dementia. Both are married and their spouses are alive but are not living in the residence. These two people have formed a sexual relationship. What is your ethical responsibility?
Overall, the seminar was a helpful introduction to the ethical issues in aged care. Ford’s philosophy of the human person underpinned the whole proceedings. His focus on the dignity of the human person as a subject was explored in the various papers. Gray talked about respecting conscience, Lyttle honed in on the rights and values of the person, and Nay focused on the rights of the elderly to take risks. Koch explored restraint and abuse in terms of how human dignity is undermined, while Garratt emphasised that people with dementia have not lost their personhood and Verity highlighted the importance of sexuality in the life of the elderly person. Barry focused on accountability and Brooks highlighted the need for staff to be familiar with their legal obligations. It was clear from the papers presented that aged care is a complex area in terms of ethical issues with a need for further discussion, debate and education of the public, politicians, and professionals. It was also obvious that carers of the aged are crying out for support on all levels. A clear message was that aged care is undervalued in society and in the healthcare system as a whole.

One of the fundamental issues in this discussion is the status of the elderly in Australian society as a whole. The elderly in western societies in general are not accorded the respect that is given to old people in many native societies. In Japanese society for instance, Keiro no Hi (Respect for the Aged) day is a national holiday. On this day respect is shown to long-time contributors to society; their longevity is celebrated and prayers for their health are offered. It is also a day when greater awareness and understanding of welfare issues confronting the elderly are discussed, and the population considers how welfare services can be improved. In Aboriginal societies elders are respected for their wisdom and their knowledge of the traditions and culture of their people. “Elders” as a term is synonymous with the notion of persons with high standing in the community, and is also used in this context in religious communities.

At a government and policy level, this issue of society’s attitude to the elderly is interconnected with the problem of fair resource allocation. The current allocation of health care funding, which favours acute care, reflects the low status that is given to the elderly within our society. Fundamental to the whole issue of aged care is respecting the dignity of the aged, their life stories, their social situation, their feelings, their spirituality, and their integrity, in spite of their diminished physical and intellectual capacities. A vital prerequisite for improvement in the care of the aged is to educate society as a whole and more fundamentally to effect a change in our society in terms of respect for old people. Furthermore this encompasses the aged with dementia and those dependent on carers for their physical needs. Generally speaking, there is an attitude in our society that those in the latter group are in some way no longer fully human.

Along with respect for people with dementia must come, by definition, the expectations we have of all members of our society, in terms of respect for the dignity and the integrity of the individual. I feel that I must question specifically the discussion of sexuality in an aged care facility. Bearing in mind that Verity was reporting what happens in some places without attempting to resolve the ethical dilemmas raised, it seems to me to be disrespectful to show pornographic films to the elderly, or to condone sexual relationships especially where there is an element of unfaithfulness within a marriage. This is treating sexuality as divorced from the integrity of the person as a whole. It appears to treat sexuality as nothing more than a bodily function, outside of the realms of a loving relationship. Teenagers have strong sexual urges without always having the emotional maturity to deal with them but we certainly should not rent pornographic movies for them to view on the premise that it will stop them acting out their urges. As for which forms of personal sexual relationships will be acceptable in aged care residential facilities, much will depend on the ethos of the institution concerned. Sexual relationships that may not be acceptable in a Catholic aged care facility may be permitted in other aged care residential settings.

Further discussion and study of ethical issues in aged care should focus on the individual and their family including any significant others in the aged person’s life. The emphasis should be on looking after the family as a whole and including them in decision making particularly in ethical dilemmas. The concept of palliative care should be applied in the care of the aged. Many professionals working in the area of aged care are striving to educate staff in the concepts of palliative care. (See Abbey J. Palliation and nursing home residents with dementia. Flinders University, South Australia, 1997 for a more detailed discussion).

Some ethical issues that were not raised in the seminar are how to define the end stage or terminal stage in someone with dementia. If a person refuses to eat should they be spoon-fed against their will or should they be allowed not to eat? What if a person is virtually bed bound, doubly incontinent, unable to communicate and respond to the family, and shows no signs of recognising family, should this be the point at which it is considered that the end stage has begun? And who makes the decision? What should be done when staff, doctors and family disagree on these questions? Living wills were mentioned but not discussed.

In summary, clearly more research is
required into the needs and goals of care of this particular group of people and the accompanying difficult ethical issues. Research is also required into the appropriate staff mix and numbers of staff required to give competent and personal care. It is also obvious that there needs to be a campaign to change the attitudes of our society to the aged. Currently, the aged care sector experiences significant staff burnout, a high turnover of staff, and has the highest record in work cover costs of any area of work. Surely the struggle for appropriate funding for aged care must be the priority of a political and ethical campaign. At stake is nothing less than the dignity of the human person and ultimately of our society.

Richard Wade BEd, STB, MA, MTheol, DTheol.
Lecturer in Christian Ethics

Overview on the Dignity of the Human Person

This is the full text of a talk given at the start of the Centre’s Conference on Ethical Issues in the Care of the Aged and reported earlier in this Bulletin.

The planning committee of this conference raised many issues that ought to be considered – and indeed much more time would be required to do justice to many of the topics on our program today. The committee decided that some reflection on the dignity of the human person should serve as an umbrella for the many issues that will be touched on today.

Many of us may have our pets, a cat, a dog or a bird. These are important for us, they give us pleasure and we look after them properly. If we can no longer look after them and nobody else wants them, though we may regret it, we would not hesitate to have them put down by a veterinary surgeon. There would be no ethical qualms about this. But there would be a storm of protest if this were to be done to an elderly person. When it is asked why it would be wrong to do this appeal would be made to the elderly person’s dignity, and rightly so. We need to ask why human persons are so special that they own us. This resentment is loudly proclaimed our awareness that we are subjects of a personal existence and not objects. The human person does not exist in the abstract without a name, family relationships, a personality, a nationality, a culture, a state of health, an age and a religious faith or a system of beliefs and values.

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To touch one’s culture or basic beliefs is to touch the person. Aged care staff need to understand fully the human person, their situation, their faith, the stages of life’s journey and their attitude to sickness and the approach of death if they are to improve their valuable professional service. This requires an understanding of the human person from a subjective perspective as well as from an objective approach by reflecting on our common human nature.

Human person: a subject centred approach

The human person may be considered in the light of reflection on our experiences. We experience ourselves as subjects in a variety of ways through feelings, pleasures, pains, growing up, marriage, family life, community relationships, recreation, social life and cultural activities. Personal worth is very much experienced in the secret intimacy of the mind and heart. We resent unnecessary and depersonalising invasions of our privacy be they blatant or ever so subtle. A human individual’s personality is pre-eminently expressed through their face. A person’s dignity, however, is also is proclaimed by modesty which requires their body be covered appropriately during ordinary social interaction.

We strive after happiness yet frequently we are frustrated, we crave personal friendships yet find we are rejected or made neurotic through the din and tyranny of the invading crowd. We seek a life of faith and love of God and neighbour yet we may be immersed in a materialistic world of self-indulgence, greed, cynicism and violence. We struggle to be virtuous
Person: human nature approach

Most of the experiences I have referred to are uniquely human, especially the awareness of our dignity. We may wonder why humans and not our pets have rationally self-conscious acts of knowledge, free choice and awareness of our unique dignity as persons. The answer is to be found, I believe, by using an objective approach to the human person and human nature. This will enable us to explain the foundation of a person’s subjectivity, dignity and capacity to be a moral agent.

The human person has to be considered as a whole in relation to all that pertains to human nature and human experience. It is by inductive reasoning, based on experience and guided by the light of sound philosophical principles, that we can acquire an understanding of the nature of the human person. Human nature is not purely biological and static. Though essentially personal and the same for all, human nature is somewhat dynamic as its significance gradually unfolds throughout history in various nations and cultures. We ever interpret anew what is good for persons on the basis of our understanding of human nature and of our expanding knowledge of ourselves and our place in the world.

The foundation for all our human experiences, capacities and human personhood is to be found in the nature of each individual. Our typical personal experiences are made possible by the inherent capacities of human nature itself. The nature of the cat or dog does not enable them to have the rationally self-conscious activities of humans or to live personal lives. Human nature includes a body and mind, a material and a non-material principle, which somehow constitute us into living individual human persons. It enables us to perform rationally self-conscious and free acts which are recognised as expressions of the autonomous person. Consequently the aged with failing memories or mental impairments are persons whose dignity and moral worth remains intact because they are still subjects of a rational human nature. This needs to be re-affirmed for all the aged in care, especially those with Alzheimer’s disease or in a permanently unconscious state. In fact, Professor Peter Singer, a prominent bioethicist, under certain conditions in principle approves non-voluntary euthanasia:

Ending a life without consent may ... be considered in the case of those who were once persons capable of choosing to live or die, but now, through accident or old age, have permanently lost this capacity, and did not, prior to losing it, express any views about whether they wished to go on living in such circumstances...

They are not self-conscious, rational, or autonomous, and so considerations of a right to life or of respecting autonomy do not apply. If they have no experiences at all, and can never have any again, their lives have no intrinsic value. Their life’s journey has come to an end. They are biologically alive but not biographically. The lives of those who are not in a coma and are conscious but not self-conscious have value if such beings experience more pleasure than pain, or have preferences that can be satisfied; but it is difficult to see the point of keeping such human beings alive if their life is, on the whole, miserable.1

However when his own mother was in this same condition Professor Singer commented: ‘Perhaps it is more difficult than I thought before, because it is different when it’s your mother.’2

and to promote the happiness of others and we may fail. Suffering and death are inevitable and reason alone fails to explain why this is so.

We identify with ourselves in a special way when we make sincere judgements about the truth, especially when we make important judgements of conscience. Likewise the exercise of free will is highly valued and reveals our personal dignity most of all when we submit to the summons of conscience demanding that we do this or that good deed to be true to ourselves as persons. We are aware of ourselves as subjects of intrinsic worth and inestimable dignity – truly each one of us one is the centre of our world. We also recognise we may not be used as mere means for others’ ends or profits.

We know that we are moral agents. We are aware of our responsibility to develop as persons through the morally responsible exercise of our autonomy. This is an aspect of our personal dynamism whereby we are ever engaged in a search for happiness and self-realisation. As relational beings we cannot be complete or achieve fulfilment except by communicating with others through knowledge and mutual acceptance. One of the highest expressions of our free will is love for another person when we genuinely seek the good of that person. It seems our personal dignity and absolute value is based on our natural capacity to seek and enjoy genuine and permanent happiness.

Notwithstanding the great variety of our experiences of body and mind, we recognise that they all equally belong to one personal subject of human existence. Our primordial and basic awareness is of a self as a complex being, one subject of both bodily and rationally self-conscious acts. We recognise other human beings are equal to ourselves in dignity, superior to animals, plants and objects. We realise that because we are persons we are important as men or women, husbands or wives, doctors or nurses, employers or employees.

Voluntary euthanasia:

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for all the aged in care, especially those with Alzheimer’s disease or in a permanently unconscious state. In fact, Professor Peter Singer, a prominent bioethicist, under certain conditions in principle approves non-voluntary euthanasia:

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However when his own mother was in this same condition Professor Singer commented: ‘Perhaps it is more difficult than I thought before, because it is different when it’s your mother.’
I suspect the experience of his own humanity made him realise it would be inhuman and immoral for him to kill his own mentally impaired mother.

Singer and others do not accept that it suffices to be an individual member of the biological species Homo sapiens to count as a person. They require some minimal capacity to exercise rational self-conscious acts, preferences and desires to attain happiness and self-fulfilment over time. Hence elderly persons who have lost entirely the capacity to exercise rational acts would no longer be persons. It is necessary to bear in mind this restricted meaning of ‘person’ employed by some contemporary bioethicists and philosophers in order to avoid serious threatening consequences. Others, including myself, following a long western tradition, argue that any living individual with a human nature, regardless of any impairment, is a person precisely because he or she is the subject of a rational nature, a subject in which personal acts may inhere.

Practical implications

In the light of a human person’s dignity, the political community should ensure that sufficient funds are allocated to provide for adequate and qualified staffing levels for the medical and direct care nursing needs of the aged. If this is not done, the government and the community would be neglecting the dignity and rights of a vulnerable group of persons, a good many of whom would have for years contributed to building up the standards of living we all enjoy. There should also be provided adequate opportunities for the aged to benefit from community interactions and social life. The privacy required by the elderly in residential care should be provided according to the

the autonomy of the aged in residential care should be respected and protected with due regard to the rights of other residents and/or the ethos of the residential care facility, bearing in mind the structures of each facility

possibilities of the different kinds of residential facilities for the aged. The autonomy of the aged in residential care should be respected and protected with due regard to the rights of other residents and/or the ethos of the residential care facility, bearing in mind the structures of each facility.

A Christian perspective

The Christian Faith complements the findings of reason on our dignity and destiny as persons. The disabilities that often accompany advancing age –

by sharing intimacy (on a variety of levels).

Young People and the Health Care System

This article briefly considers several areas where health care services and initiatives need to be specifically aware of the unique characteristics of young people.

Young people and adolescents

Adolescence has generally been used to describe the developmental period of approximately 12 to 18 years of age. I will use the term interchangeably with young persons. However, the term young persons is generally used to refer to the broader 12 to 25 year age bracket and attempts to remove much of the derogatory or patronising use of the
term adolescence. Adolescence is a period of great change. The mode of thinking changes from reliance on object or imagery for problem solving to comprehension of abstract concepts such as those used in philosophy.

It is also the time individuals often question old values and move gradually towards a mature sense of identity and purpose. Social development around this time sees individuals attempt to establish and maintain personal relationships

Youth health issues

summer 2001 – 2002

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Young people experience many of the ‘usual’ and everyday health problems suffered by the rest of the community such as colds and other viruses. Some young people must also learn to manage long term health problems such as asthma and diabetes. However young people are vulnerable to a number of specific health risks. This stage of life is often associated with instability and experimentation and factors such as employment, income and accommodation can all further impact on the health status of a young person. These can be either immediate risks or the start of long-term behaviours which may result in health problems later in life. The major health risks for young people include: death or injury as a result of motor vehicle accidents, falls and poisoning; poor emotional and mental health; risk-taking behaviours; and lack of access to health services.

Young people often require immediate intervention and assistance to help them deal with health risks that pose immediate danger. This requires health services to be readily accessible to young people. I will discuss next the need to promote confidentiality and tolerance as a way of inviting young people to seek help as soon as possible. Adolescence is also a period of development that provides an opportunity for effective health promotion. Highlighting to young people the advantages of living a healthy life style while also identifying behaviours that pose major health risks can be done effectively if delivered in a youth friendly manner.

Immediate health risks

Behaviours that pose immediate risks to health often require urgent medical attention. Such types of behaviours might include drug taking, road accidents and other activities that involve the risk of falls. Young people need to feel they can seek treatment for these types of problems without fear of judgement. If a young person knows that interactions they have with health care professionals are confidential then they may be inclined to seek help before their behaviour or that of peers reaches crisis point. However, if a crisis is reached a young person needs to feel confident in accessing the necessary health care without fear of unnecessary repercussions.

Long term health risk

Encouraging young people to live a healthy life style and helping them identify their own health risk behaviours can be a very difficult task. Often authority is questioned and any opportunity to demonstrate rebellion is eagerly accepted. This increases the need to ensure that any interactions young people have with the health system are positive and that where possible simple health promoting messages are delivered. If a young person is seeking advice because they are suffering continual cold symptoms or stress related to their study or employment situation then health professionals can offer advice on dealing with stress, the need for sleep and healthy eating tips. This advice can be invaluable not just to help the young person through their current poor health but may also help to prevent them from becoming sick next time. Other health promoting messages such as the risks of drug taking can be broached in very sensitive ways. It is worth noting that the initial reason given for making the appointment with a doctor may not be the ‘real’ reason the young person is seeking help.

Access to health care

Young people should be made aware that they can access health care services without the need to involve their parents. To assist in this way doctors can bulk bill young people and can even help them to find out their Medicare number or to apply for their own Medicare card (if they are 16 years of age or over). Doctors should also be conscious of making their waiting room and surroundings friendly to young people. It is important to make young people feel welcome and relaxed. Providing seating that is not too close together and appropriate reading material is one way of helping young people to feel relaxed.

In all interactions with patients it is essential that health professionals use language that the patient understands. If the patient does not speak the same language as the doctor then an interpreter will be required. Some might argue that many doctors and young people don’t speak the same language, but it is unlikely an interpreter will be needed. Doctors need to explain clearly and accurately all the information a young person needs to understand their health status and to make any treatment decisions that may be necessary. The consultation will also be helped if health professionals appear interested in the young person and ask relevant questions in non-judgemental ways.

Consent and treatment decisions

It is important to ‘encourage the involvement of young people in the services decision making and planning processes’. Young people need to feel they have some control over their interactions with the health care system, although their control is as limited as everyone else’s when it comes to the health system. Highlighting the range of options and choices available and explaining the referral system for specialist services are essential in making sure young people receive the best care possible and that they can make the best possible treatment decisions in their given circum-
In the past the law set certain age limits for consent to medical procedures. They now employ the principle known as ‘the mature minor test’ or the test of ‘Gillick competence’. The principle follows a judgement that states, ‘A minor is … capable of giving informed consent when he or she “achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed”’. This standard applies to all interactions with the health system from prescribing medications to more major interventions. The flip side of consenting to medical treatment is that patients also have a right to refuse medical treatments. Even in cases where a parent may be legally entitled to consent to treatment on behalf of their child doctors should not proceed without the consent of patients who are older than 14 years of age. ‘The refusal of a “minor” over the age of 14 years to undergo treatment must be respected…’. These kinds of situations are difficult for families and hopefully occur very rarely. If adolescents are treated with respect, and consulted about their wishes regarding treatment then perhaps they and their families can reach decisions upon which they all agree.

Confidentiality

Confidentiality refers to the requirement of protecting information given to health professionals (or others) in confidence. Health professionals have an obligation of confidentiality. They should not disclose information to another party without the patient’s consent. This requirement stands even if the third party is the patient’s parents or guardians. Exactly what age or level of maturity a young person needs to be in order to have a confidential relationship with their doctor is uncertain. I think a young person who is old enough to value their privacy, understands what is going on and feels the need for confidentiality should have their wishes respected. Young people should feel reassured that, ‘it is not necessary for a doctor to contact the child’s parents and the child is entitled to the same confidentiality of medical information as an adult patient’. This standard is similar to the ‘mature minor’ test mentioned above. As with every rule, there are exceptions. If the confidential information relates to potential harm to the young person, in the case of sexual or physical assault, then confidentiality can be broken in order to prevent further harm. This should only be done if, after encouragement and with support, the young person will not voluntarily share the information with the appropriate people. Confidentiality can also be broken if health professionals think a patient may pose a significant health risk to a third party or themselves. This duty to warn others of potential danger applies not just in situations where the patient is a young person but also when the patient is an adult.

Conclusion

Issues of confidentiality, consent and access are only some of the specific problems related to young people and the health care system. Young people often have unreasonable expectations of doctors. The results of a survey of some Year 7 students found that GPs were expected to know about everything from blended families and homework to steroids, alcohol and drugs. With these kinds of expectations it’s not surprising that young people are daunted by their interactions with the health system and its practitioners. At the same time doctors are often unsure how to relate to young people but are cognisant of the complicated issues they face. The AMA notes, “Some GPs find it difficult to deal with young patients, and in turn many young patients find it embarrassing to talk to their family doctor about intimate problems.”

In addition to dealing with the day to day health problems many GPs are faced with helping young people and their families through times of crisis and these situations can generate complicated ethical and legal responsibilities for health professionals. One way to encourage young people to access health services before reaching a crisis situation is to ensure that they are aware of the services available to them, know that services will not be expensive and feel welcome. These aims might be best achieved using focused health services for young people. Such services promote GPs in the community or in their own centre who have ‘expertise’ in dealing with young people. Like all medial specialities concentrating expertise is invaluable. Perhaps not all GPs are best suited to relating to young people but by identifying those who are we can help both doctors and their young patients.

ENDNOTES

4 Principles for service provision for young people, Clockwork Young People’s Health Service, Geelong Victoria.
6 V Plueckhahn, K Breen & S Cordner, Law and ethics in medicine for doctors in Victoria, (Geelong: VD Plueckhahn) 106.
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Tracey Phelan
Available end of January

Human Embryo Research, Manipulation & Ethics

Proceedings of a conference held at St Vincent’s Hospital Melbourne on 24 May 2001

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Caroline Chisholm Centre for Health Ethics
7th fl., 166 Gipps Street East Melbourne Vic 3002
Tel (03) 9270 2681 Fax (03) 9270 2682 email: ccche@mercy.com.au www.mercyhealth.net/chisholmhealthethics/

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Research Officer:
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