Inquiry by **Parliament of Victoria**

END OF LIFE CHOICES





Note please: the illustrations and design of this document are purposeful. The intent is to focus on the human beingand what is required to allow us to be all we are for all our days even when we have no voice.

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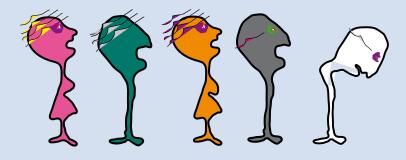
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1 Introduction

Our position is that 'End of Life' is within a continuum of 'Whole of Life' which arise before, during and after end of life, including after life ie 'Right of Internment'.

Bourne and Associates welcomes the opportunity to present this paper to the **Parliament of Victoria**'s call for submissions into the **Inquiry into End of Life Choices**, 2015.

The reality is, legislative change is needed - we need to spend more to ensure a quality system with related legal and medical services. This, it seems, we are not prepared to do.

... the cost is born by those who are ill, are elderly ('baby boomers') and do not have the capacity to vote, advocate, speak, act for themselves.

Reasons for change: human rights argument, ageing population (argument that the baby boomers are unlikely to accept the default low quality of care as they age and move into residential aged care facilities (RACFs) and the dignity argument.

The starting point is 'human beings' - defining problems, then set about finding innovative solutions that fulfil the needs, wants and desires for the benefit of the individual, the collective, the community, our nation.

This reality necessitates new ways of working, new ways of thinking.

Our findings reveal that there are occurrences where the current legislative framework is not appropriate for Victoria's citizens as we move into a modern and contemporary Victoria in the twenty-first century.

It is through the Parliament of Victoria that legislative change can, and should, occur to meet the demands of the new reality.

In this paradigm, it is fundamental that we do not merely replicate and rehash existing policies and systems (models).

A diagnostic and forensic approach is required to determine the human element for "Whole- of-Life/End of Life Choices".

In this context, we strongly urge the Parliament of Victoria to design innovative solutions and the legislative changes that impact value to its citizens: to be all we are for all our days - even when we have no voice.

...unified and coordinated efforts at the national level must continue to preserve and protect the human rights of vulnerable aging populations.1

Dong, X.Q. (2015) Elder Abuse: Systematic Review and Implications for Practice. American Geriatrics Society, 63, p1235.





To be all we are for all our days - even when we have no voice.

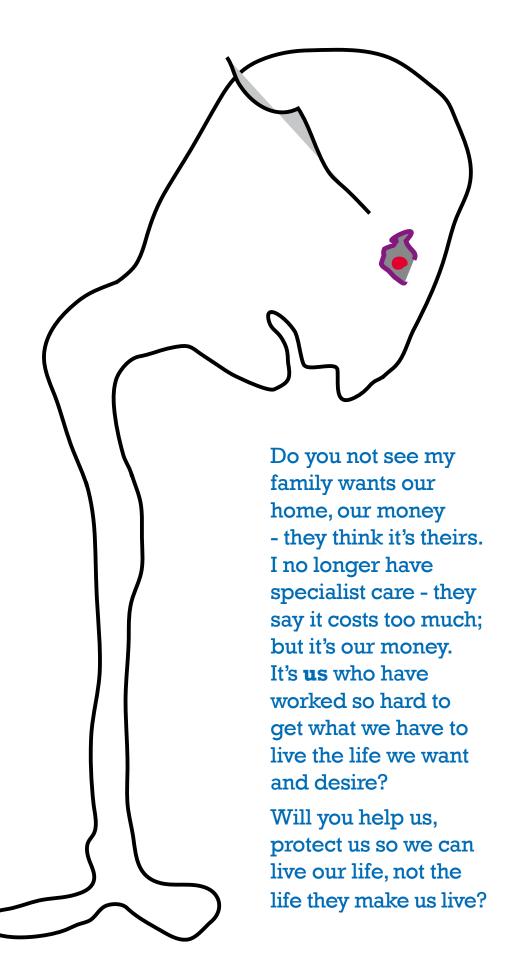
2 Overview

We know the number of elderly is rising and will continue to do so as 'baby boomers' retire and age. In due course circumstances will arise which will impact even further on our nation (economy, education, medical and legal), communities (urban, regional and rural), families and individuals.

Whole-of-life There has never been a more critical stage to confront the challenge of addressing issues related to, we contend, 'Whole of Life', rather than 'End of Life' - caring for a generation of older Australians who has better health, more wealth, an independent spirit and an expectation of whole-of-life care being given that recognises their individual needs, wants and desires than any previous generation.

This requires a fundamental change in attitudes, in prioritising and expanding the existing funding in health care, education and training, making appropriate regulatory changes and delivering media campaigns to change perspectives of the value of our older citizens from a cost to the community to an investment that has no greater need than determining our own value as human beings.

Since our earliest beginnings, societal beliefs and values have travelled from generation to generation. In understanding that people cared for others who had impairment through illness or injury by providing, at the most basic level, sustenance, shelter and rudimentary medical assistance demonstrates that an individual was valued by that society. If a person could not source food and water, create a shelter, or other activities that required physical attributes, then their value was through accumulated wisdom, knowledge and/or emotional fulfilment. The journey of what it was to be human began and the journey continues.



I see. I hear. I feel. I feel, I want and desire. I speak... but do you have the patience, the time and the ability to understand me in the way I am now that is different from before?



3 Catalyst for Change

The following arises out of experiencing a range of limitations and inadequacies of the system that impact directly on the life of the aged person and family members.

This entails recognising the felt impotence, powerlessness and the seeming conspiracy of a cone of silence.

The following pages set down key issues that underpin what is required for an ageing population that is expanding with new needs developing ('baby boomers'):

- In how they are treated and their needs met.
- · In how the law deals with their rights.
- In the range and capacity of services to meet their needs.

Our 'identity' is grounded in each human being's unique character - his/her needs, wants and desires and the right to have these met through their whole-of life journey. When the actions of others take away these rights, this is 'Identity Abuse'.

Whatever the effort to tackle this form of abuse, it is needed and necessary - to be all we are for all our days, even when we lose our voice. Am I of so little value and less than you because I have ill-health and the years make me a little greyer?



4 Identity Abuse

Definition



An inadequate range of care and responses to needs, wants and desires which runs mostly, or totally, counter to an individual's sense of identity, self-concept, lifestyle preferences, priorities and choices.¹

Note: 'Identity abuse' is not only limited to lack of respect, lack of quality and lack of dignity.

A 'sense of identity' is integral to each human beings character- his/her needs, wants and desires and how these are met through our whole-of life journey, which is not exclusive to end of life.

We support a notion of 'identity abuse' to be where there is an inadequate range of care and responses to needs, wants and desires of older Australians which can run mostly, or totally counter to, an individual's sense of identity,self-concept, lifestyle preferences, priorities and choices.

It includes either errors of omission as well as comission, and whether an older

Extract:

Eat Bananas. Identity Abuse in the Care of Older Australians. Bourne and Associates, 2010, page 1. Submission to the Productivity Commission, Care of Older Australians.

individual is aware or unaware, results in 'disempowerment' and at worst, assumption and/or denial of their rights as a human being.

This abuse stands at the essence of who we are as individuals - our identity and the right for self determination regardless of age, language, religion, gender, health, sexual orientation, socio-economic status and ethnicity with each having their own unique identity.

We reject the notion, that because there may be difficulties in constructing legislative and other safeguards to address this form of abuse, that the abuse has to continue unabated.

We strongly recommend that action is warranted as lives are being impacted now and with the increasing number of baby boomers reaching older age in the months and years to come, it is our contention that the abuse will continue to grow.

Whatever the effort to address this form of abuse, it is necessary to tackle it for to do otherwise is to diminish us all as it stands at the core of humanity and civil liberty.

Be not mistaken, in our experience, families take away the rights of those they are given duty of care.

Individuals have spoken to the authors about their parents, grandparents, aunts, uncles and friends who have, and are being, subjected to Identity Abuse.

I want my privacy, my own bed, to sit on my comfy chair, feel my fluffy sheets in my own bed. I'm angry, frustrated, afraid, powerless - I tell them the only way I know how. I yell, I flay my arms, I scream. They choose to not understand. The doctor says I'm psychotic and wants to prescribe Risperidone - does he know what that can do to me? Or doesn't he care as long as it keeps me seated, keeps me silent? I'm not psychotic, I am just telling you in my own way what I want and what I don't want. The money's there in the equity in my home to take care of me so I can live the life I want.



Their views have informed this submission. Their response to being identified by name was negated by all, therein, their responses are confidential.

When talking about their situation, the common response was guilt, disempowerment, despair, resignation, secretiveness, anger and/or the notion of unfairness.

They strongly support Bourne and Associates actions to formally acknowledge 'identity abuse' and the steps to have this form of abuse acted upon, especially regulatory arrangements.²

Extract:

Recommended for Action

- Add 'Identity Abuse' to the existing list of abuses in Australia and at international level including the United Nations, so peoples globally may benefit.
- 2. Generate innovative solutions that are purposefully designed to address Identity Abuse.

² Eat Bananas. Identity Abuse in the Care of Older Australians. Bourne and Associates, 2010, page 2. Submission to the Productivity Commission, Care of Older Australians.



I am a feisty woman who votes as she thinks fit - and in a different direction to my husband. My elder daughter had always voted as "Daddy" told her to do. That daughter helped me fill out my postal voting papers and made sure that I voted for the "correct" party. How's that for identity abuse!

5 Judicial, administrative, legislative

5.1 Auditing

"Who guards the guardian" - ie those who hold Guardianship/Power of Attorney. It is our contention that the *Powers of Attorney Act 2014* that commenced on 1 September 2015 does not address the requirement of auditing ie auditing to ensure the responsibilities and duties are carried out as set down in the legal document.

5.2 Guardianship/Power of Attorney authority

Who can apply for Guardianship/Power of Attorney and who is informed prior to person/s being granted the authority ie one family member applying and being granted authority without siblings or other family members being notified prior, during or after being granted authority.

5.3 Medical · Capacity

Particularly focusing on enduring Guardianship, Powers of Attorney (financial, legal and medical), as well as matters concerning privacy and informed consent ie when a person has capacity/does not have capacity.

5.4 VCAT

Changing the current policy of VCAT that

withdraws proceedings when the person dies before the matters are concluded ie matters that are not resolved and have implications other than for the deceased.

5.5 Reporting

In our view there are impediments to a transparent and satisfactory outcome when making a notification to AHPRA.

The Health Practitioner Regulation National Law Act 2009 (National Law) restricts information that can be provided to those who submit a notification to Australian Health Practitioner Regulation Agency (AHPRA).

The consequence of this is that the notifier/s can be provided with brief and inadequate response to their concerns.

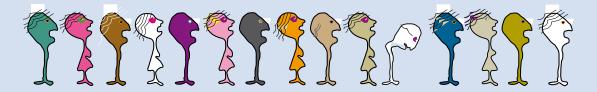
Additionally, notifier/s are prevented from discussing the outcomes of the notification with anybody, including family.

The process lacks transparency:

• Notifier/s - lack of information.

For notifiers it can be a process that is thwart with frustration and immense emotional stress arising out of the circumstances that led to the notification





Rights to our privacy are not up for grabs!

being lodged, the longevity and complexity of the AHPRA process and then being unable to find out about the details of the findings and the lack of transparency.

 Currently, notifiers are considered a 'member' of the public' and, therein, are not advised of the <u>full</u> results of their notification.

Notifiers notify because they have had an injustice done to them. Those suffering an injustice notify AHPRA and as such are not a 'member of the public'. The notifiers have a vested interest in being fully informed of the outcomes of AHPRA's findings.

 Incomplete information for Australians seeking the services of health practitioners.

When Australians are seeking the services of a health practitioner, they require information such as to be fully informed about the professional competence and conduct of the individuals they are selecting.

Omitting from view details of misconduct or malpractice could reasonably put the public 'at risk' or 'negligent responsibility' regardless of any 'privacy considerations'.

In the present circumstances dealings within AHPRA processes might be seen as denying a just and satisfactory outcome, especially for the notifier.

Recommended for Action

- Change the Health Practitioner Regulation National Law Act 2009 (National Law) to be a transparent and just process.
- When there has been a notification, list the findings and 'actions taken' on AHPRA's 'Registers of Practitioners'.
- 3. The results of notifications are listed on AHPRA's 'Registers of Practitioners'.
- 4. Notifers to AHPRA are to be fully informed of the <u>full</u> results of their notification and they are not restricted from speaking about their notification.



Yes, from when they were small and into adulthood, I have spoken to my children about what I want in my older years should I become ill ... they promised I would always live in my home and they would take care of me there in illness and old age - such has it been with all our family.

My daughter, who had moved back into my home, packed my bag and led me out of my own home, drove me to an aged care facility and left me there never to return to my home, my beloved home - the place that is mine to be on this earth. I plead looking into her eyes saying again and again, "Home". "Home".



Note: She died less than a year later; not of Alzheimer's, disease, but heart failure in the age care facility, not in her own bed, her own home. She had the resources to do so.

Who guards the guardian?



My brain is just another body part. Would you treat me as you do if I lost the use of my arms, my legs, my kidneys, my eyes, my hearing? So don't make me suffer even more and treat me as if I'm gone. I am me and I'm here.

6 Medical Matters

6.1 Relationship between GPs and specialists

The working relationship between GPs and specialists - assumption of responsibilities? Who? When?

6.2 Medical Practice and Continuity of Care

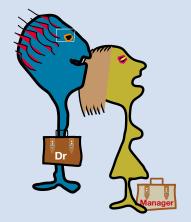
Medical/agency staff within care facilities and the relationship to GPs and specialists' treatments and medication including ongoing and up-to-date knowledge of drugs especially their applicability, side-effects and monitoring.

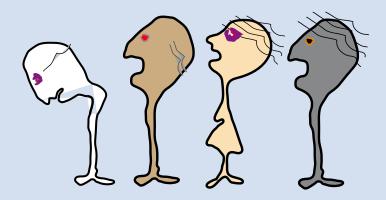
Recommended for Action

- Specialists and GPs cannot sign a POA and Guardianship to one or more family members without all the family members having knowledge of and having the opportunity to be signatories to any POA or Guardianship.
- 2. We contend that there is a significant gap between the interface between how medical POA is defined and how lawyers define responsibilities ie standards, a program of Continuous Quality Assurance (monitoring/assessing/auditing) that is administered by an independent authority to ascertain that the medical

POA is actually being delivered.

- Registration of medical POA with some central public medical authority with copies to family members.
- 4. Conditions to be placed on availability of information and privacy. Family members should have no right to medical information on capacity until it is clear that incapacity is demonstrable by more than one appropriate specialist.
 - "Rights to privacy are not up for grabs!"
- With increasing research on Alzheimer's
 Disease and concurrent syndromes/
 disabilities, the progress and states/
 stages need to be more adequately sign
 posted for demonstrable professional
 determinations of incapacity.
- 6. Where there is an on-going medical condition eg Alzheimer's Disease, the person holding the medical POA cannot stop treatment given by a specialist unless the treatment is demonstrably not contributing to the health or well-being of the patient.
- 7. The specialist granting or signing off on a medical POA should have, thereafter, all over-riding responsibility and 'duty of care' in respect of medical matters including drug administration especially prescription drugs.
- 8. Nursing home GPs and other private

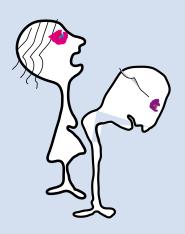




GPs and relationship with specialists

- a **Management Plan** for each resident detailing overall care management and relationship with aged care facility/nursing home and GP/specialist.
- 9. Regulations governing the ability of GPs to provide prescription drugs without up-to-date knowledge of the appropriateness of the medication, and their side effects.
- 10. Care facilities within the Management Plan, medical staff with the appropriate level of training to be actively responsible for monitoring changes in the patient's

- condition and call GPs and/or specialists for assessment without delay.
- 11. Following the administration of prescription drugs GPs and/or specialists are responsible for the monitoring and assessment of the patient within a planned and co-ordinated program 'Management Plan'.
- 12. GPs who attend patients in private homes and care facilities to have regularly up-dated and certified training in medical conditions and related prescription drugs associated with the elderly.



When I'm happy, or sad, I clap my hands for a few seconds and say out loud, 'Ahhhh'. They don't like that. I've always walked, never had a car. I like walking in the garden. They don't like that either. I swallow. The pill goes down. I don't walk any more, or clap my hands. I can't talk any more, not even 'Ahhhh'.

7 Antipsychotic Drugs

Lateline, 16 August 2012. Mark Butler, Mental Health and Ageing Minister stated that there is very significant use of anti-psychotic medication, essentially for behaviour management, rather than psychotic disorders.¹

In a study published in The Lancet Neurology, 'The dementia antipsychotic withdrawal trial (DART-AD): long-term follow-up of a randomised placebo-controlled trial', the authors stated, *There is an increased long-term risk of mortality in patients with AD who are prescribed antipsychotic medication; these results further highlight the need to seek less harmful alternatives for the long-term treatment of neuropsychiatric symptoms in these patients...'*

Another study published in **Journal of the American Geriatrics** 'Antipsychotic Drug Use and Risk of Pneumonia in Elderly People' the authors reported, *Use of antipsychotics in elderly people is associated with greater risk of pneumonia. This risk is highest shortly after the initiation of treatment, with the greatest increase in risk found for atypical antipsychotics... ³*

Numerous papers have since been published that support the above views and findings (see Sources: p23, 24).

Safeguards ie policies and processes are required to protect individuals who cannot speak for themselves, and those, for a variety of reasons, are unable to take action to protect those who cannot speak for themselves due to:

- Care less attitudes and actions.
- Secretiveness by those who do not provide full disclosure of what is being administered.
- Inaction by family members/friends arising out of guilt, grief, despair, anger, resignation, disempowerment.

www.abc.net.au/lateline/'Butler joins Lateline', 16/08/2012

² Ballard, C., Hanney, M. L., Theodoulou, M., McShane, R., Kossakowski, K., Gill, R., Juszczak, E., Jacoby, R. (2009) The dementia antipsychotic withdrawal trial (DART.-AD): long-term follow-up of a randomised placebo-controlled trial. The Lancet Neurology, 8 (2), 2009, 151–157.

³ Van Marum, R. J., Jansen, P. A. F., Souverein, P. C., Alfred F. A. M. Schobben, A.F. M., Egberts, A. C. G. (2008) Antipsychotic Drug Use and Risk of Pneumonia in Elderly People. Journal of the American Geriatrics Society, 56 (4), 661–666.



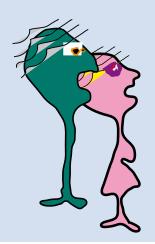


I stare. My fingers are stiff. I forget to chew now. I see her; she cuddles me, holds me; she can't take me home with her, she's not allowed; her eyes are wet. Soup. She puts a spoonful in my mouth. I hold it in my mouth. She tickles my cheek with her finger. I swallow. One word. One word, "Beautiful", I say and our eyes bathe in each other's love. She leaves. I lay me down to rest now. My heart beats no more.

- Belief that GPs, specialists and care staff are acting in the best interest of the individual.
- Ill health.
- Fearful to speak out lest there be repercussions for their relative in care.
- Intimidation by family, medical and/or care staff.

Recommended for Action

- Remove antipsychotics eg Haloperidol and Risperidone from the current range of drugs administered to control behaviour when there is no psychosis in dementia and Alzheimer's Disease patients.
- Antipsychotics and other prescription drugs be restricted to specialists for those who have Alzheimer's Disease and other illness which renders patients incapable of speaking for themselves.
- 3. Mandatory monitoring and reporting when patients are administered prescription drugs between GPs, specialists and aged care facilities, nursing homes or private residences.



I am just a little older, and ill ... but I am all that I was before - I still don't like bananas, they make me feel ill; I still love designer clothes, but I don't wear them any more; I love to hold my daughter in my arms and sit in the sun with her, I feel the warmth and so much more. I am me and I'm here.

8 Communication Inventory

'Communication Inventory,' otherwise referred to as 'Advance Care Planning' or 'Instructional Directives'.

Each of us are multidimensional beings. For those, who due to illness or injury, cannot voice their needs, wants and desires, we recommend that an inventory be designed to document his/her choices and that it be used to direct management.

Recommended for Action

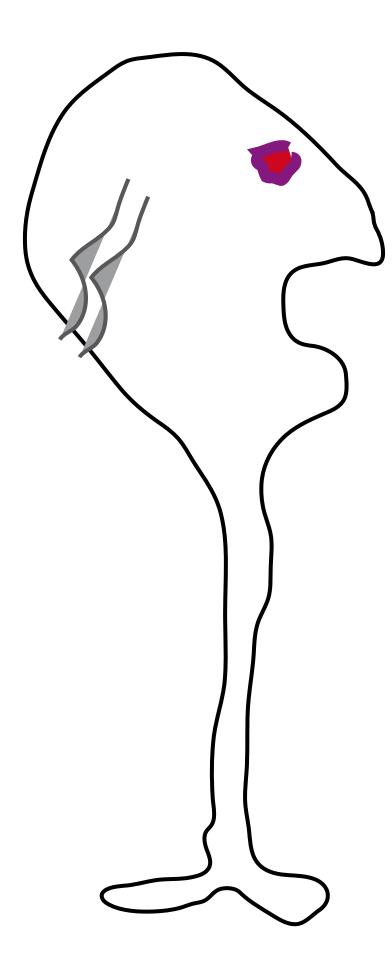
- Binding instructions. The inventory is to be a legal document to be delivered and sustained for whole-of-life such as at an appropriate time this can be referenced within a likely prognosis for future need for care such as a diagnosis of Alzheimer's.
- 2. 'Communication Inventory' will necessary be fulsome in its content covering legal, medical, well-being and life style needs.
- We submit that sustaining an individual's sense of identity (and preventing abuse) is not an aim, but a **necessity** invested with the person/body with Guardianship/Power of Attorney authority - please refer to the 'Guardianship'.

Advance Care Planning', Chapter 11: whole-of-life planning, there are those that have vested interest and do not provide the care the person requires to live the life they wish regardless of their age, health... (p206).1

It is not to be an Inventory that 'aims' to deliver, but actually delivers. The Inventory will require the highest level of systems management to deliver what is required. Equally it will require accompanying training along the Value Chain from management-to-carer-to-person.

3. If the cost to implement the 'Communication Inventory' cannot be met by the individual it will be met from public funds.

¹ The Victorian Law Reforn Commission's *Guardianship: Final report* (18 April 2012). Retrieved: July 2015. www. lawreform.vic.gov.au/projects/ guardianship-final-report#.dpuf



I'm a farmer you see.

I really **have** to see the sky, feel the wind, see the clouds, smell the air - is it going to rain today? I lay in my bed and look to the light, but I can't see out. They've nailed the net curtains, so I can't pull them back.

I look down at the floor.

My niece visits; she twists the curtains back and ties them with a towel to hold them. I can see the sky, the plants, the clouds - it's windy.

Tears creep along my eyelid and slide down my cheek.

Her worried face studies mine, 'Are you Ok?' she asks. I just grip her hand in mine and hold her close, for I know when she leaves so will the sky.

My sister is in another place - she looks at the floor like I do; that's all there is.



I'm so very cold. Why don't you dry my hair? The water is dripping and soaking my clothes. My elder daughter talks to you - you tell her it's too costly to dry my hair. She says she'll buy the hair dryer - and she does, why won't you use it? I'm so very, very cold...

9 Well-being

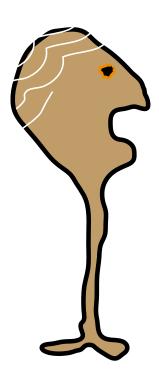
Definition - the state of being comfortable, healthy and happy.

Provide living environments in which an individual's preferences are delivered to meet his/her life style and life choices from living spaces, food, music, clothing, activities, furnishings and more (see next page please).

To ensure an individual's well-being, the person needs to communicate with those looking after them whether in their own home or other environments such as aged care facilities.

Recommended for Action

• Communication Inventory (p14) - a list of each item required so that individual receives the care they need, want and desire.





Extract: Eat Bananas. Identity Abuse in the Care of Older Australians. Bourne and Associates, 2010, page 7. Submission to the Productivity Commission, Care of Older Australians.

6. Are these not simple needs?

Maslow's Hierarchy of Needs segments the areas which relate to an individual's well being and health (see attachments). Identity abuse, in its various manifestations can be aligned to each layer from basic physiological needs such as food, sleep through to self-actualisation. Our views support the findings of CJ Scholzel-Dorenbos, et al.¹

Are these not simple needs?

Well, actually no - when it comes being elderly and cannot speak for yourself.

Individuals have spoken to the authors about their circumstances. Some of their stories are below. One individual writes:

In my own family, I observed this [identity abuse] with alarm with regard to my mother's care. After she had an illness which meant that she had difficulty coping alone at home, games were played to get her to change her executors - without discussion between the siblings. Transferred to a lower order nursing home, very much against her will, when she could have been cared for at home (concern about eroding the (modest) inheritance being a likely reason).

But there was another form of identity abuse - Federal election. My mother was a feisty woman who voted as she thought fit - and in a different direction to my father. My elder sister had always voted as "Daddy" told her to do. That sister helped her fill out her postal voting papers and made sure that she voted for the "correct" party. How's that for identity abuse!

Others' experiences are:

Change Attitudes

I was talking to the head nurse at the nursing home about my mother's intense dislike for bananas, even to the point of making her feel physically nauseous. The response - she doesn't remember she doesn't like bananas. My mother still has bananas set before her.

On another occasion I expressed my wish to spend even more time with my mother. The response - she doesn't remember if you are here or not, when you last visited, or if you visit at all. Your concerns about how frequently you visit are about your own needs, not hers. How wrong she is. My mother stands up tall, her face and eves shine, she hugs and kisses me and holds tightly. She knows when I am leaving and sadness engulfs her whole body; she hangs her head; her eyes dim; she knows and feels. You just have to have patience to observe and learn other ways of communicating.

When I had my voice	I can't verbalise my needs, so this is my life today					
My home was my haven, my safe place, it is the one place I want to be in this world. To pay it off and own it was a monumental task. My children promised to never put me in a nursing home, but look after me in my own home as our family has always done with our elderly.	I'm in a nursing home. One of my children put me here. She moved back in with me and now she believes my home, that I paid for, is hers. She doesn't want carers in the house. Now I'll never sleep in my own bed again. I can still say a few words. I tell them, "I want to go home". No-one listens.					
I always dry my hair after showering or bathing.	They have showered me and now I'm sitting in a chair with wet hair. I'm cold.					
I don't like fruit, most especially bananas, except for fruit when it is in an apple pie, a cake or lolly.	Even though my daughter told them about my intense dislke of bananas, they still serve it to me.					
I have always worn best quality clothes, especially designer labels, I was a model.	I wear op shop, or low end department store clothes now.					
I've never worn track suits - no style.	I now wear pull on track suit pants.					
I've always worn jewellery - love it.	My jewellery was taken from me.					
One of my children took out a Power of Attorney. [As advised by her specialist doctor, medically this individual did not have the capability to consent and was not a signatory. Furthermore the specialist was not consulted at any stage during the process of obtaining the authority, nor was a signatory.]	I have lost all say over my financial matters including my home and the daughter, who I asked and has taken care of my money over the years, didn't know about this Power of Attorney until years after the papers were signed.					

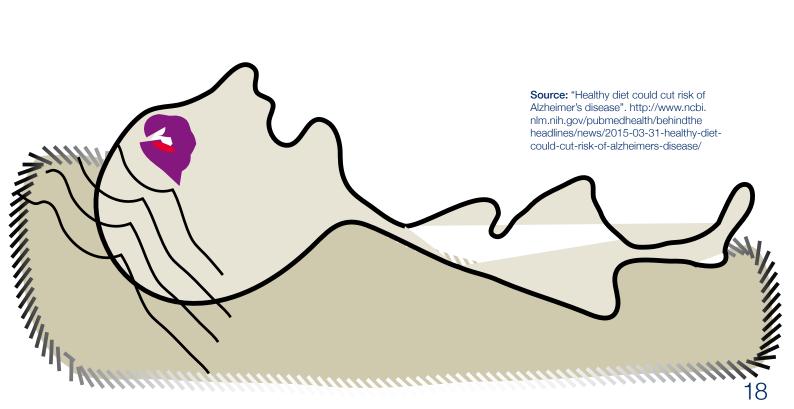
Scholzel-Dorenbos, C. J., Meeuwsen, E. J., & Olde Rikkert, M. G. (2010). Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. Aging Ment Health, 14(1), 113-119.

Hands washing me, no, oh no! Drying me, dressing me, seeing me without my clothes on. Please. No.

Where is the warm jumper bought for me - it's gone so is my make-up, my jewellery and perfume. Where is the food to nourish me?¹

Everything has been taken from me. I weep silently. Home. I ask and ask until in the end I know you won't let me go home will you?

I'm now a prisoner where I lay.





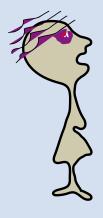
I need knowledgeable and skilled people caring for me. Do you think less than a couple of months training is all I deserve? Do you think that's all I'm worth?

10 Workforce Requirements

Quality services and integration of education/training at every level from carers to GPs, specialists, as well as management and administration from basic courses to life-long learning and career paths.

Recommended for Action

- Further investment of funds to upgrade quality education and training in both home and supported care particularly in regard to those with Alzheimer's Disease, dementia, aged care in general, elder rights and identity abuse.
- 2. Increase the number of specialists psychogeriatricians, psychiatrists, geriatricians and neurologists.
- 3. Create an innovative program to attract under-graduate medical students to the aforementioned specialist practices.
- 4. Delivery of education and training at every level from basic courses to life-long learning.
 - The poor quality of training in some sectors of the aged care workforce requires urgent attention. This is evident in the example of care attendants who may have as little as 6 weeks training.



Why is there no headstone on my grave? Do you not honour me, celebrate my life ... love me?

11 Right of Internment

From our understanding, the 'Right of Interment' is held by the person/s who pays for the grave site. This 'Right' can have significant and on-going impact and consequences for the person interred and other family members.

In our view, we believe the current regulations are weighted on side of the person holding the 'Right of Internment'.

The regulatory bodies:

- Cemeteries Trust. We understand that the current process is not conducive to appeals being granted.
- VCAT. Placing a 'Right of Internment' appeal before VCAT places significant financial and emotional burden on the applicant, and the outcomes are uncertain. More often than not appeals are not made as it is a better choice to avoid the stress and cost consequences against an outcome that is uncertain.

Only the signatory/s to the 'Right of Internment' has authority; all other persons including family members have no rights.

As the 'Right of Internment' is passed on by the signatory/s upon death to a person of their choice, other family members are excluded for all time.

The power that the person having 'right' has exclusivity.

Recommended for Action

- Mandatory disclosure. A mandatory process that advises family members (inclusive of spouse/partner and all children of the deceased) of the 'Right of Internment' and their right to be signatories.
- 2. Appeal process. When matters arise out of the above disclosures not being met, a family member may appeal and where, appropriate, retrospectively. Family members particularly his/her spouse, children and/or parents can be granted a 'Right of Internment' that recognises their rights eg to place a headstone or commemorative plaque on the grave site if the signatory has denied it.



In the months, decades and ages to come no-one will be able to find mum and her brother, and be where their beautiful bodies lie and know them, weep for them, remember them, tell their stories, smile, celebrate and honour them. Is this morally right or justifiable?

Case Study

On Sunday drives mum would have her brother stop the car to look at cemeteries in towns and along the road-side. She loved reading the headstones of those who had passed. And even more so about our family who have passed away.

Mum and I spent many hours searching the grounds and records of cemeteries for the grave sites of our loved ones - we would sit and talk to them and about them, recount stories of their lives and say the 'Lord's Prayer' together before leaving...

About Angels.

During our visits to [her grandfather's] grave, we drove past a beautiful monument and mum would say, "I want that on my grave". She pointed to a huge, exquisite angel.

I would retort, "I'd have to sell my house to buy that sculpture"! She would laugh joyously, and meant what she said, "Don't care, that's what I want."

Now the time has come to place a beautifully sculptured angel on her and her brother's grave, but I cannot; her son holds the 'Right of Internment'. He will not give his permission and this decision is supported by her other daughter - so my beloved mother lies in an unmarked grave beneath an expansive lawn.

I have implored my siblings, talked and written, sought and paid for legal advice and work - all to no avail. He owns the 'Right of Internment' and is using it for personal motives to the detriment to the wishes of our mother, and as our lawyer wrote to me, "I could not extract any rational reason for the refusal to agree to the memorial. There would appear to be none...".

Extract: "Love Never Fails". Carolynne Bourne. June, 2015 (a family history publication)





Whatever the effort legislatively and economically to tackle the issues raised in this paper, we urge the Parliament of Victoria's 'Inquiry into End of Life Choices' to deliver the items 'Recommended for Action' that enable us to be all we are for all our days, even when we lose our voice.

12 Conclusion

As we move into a modern and contemporary society in the 21st century, the Parliament of Victoria needs, and should, determine the necessary changes to legislative framework where it is not appropriate for Victoria's citizens who through illness, or other impediments cannot speak for themselves.

In brief:

- Human rights. Add 'Identity Abuse' to the existing list of abuses in Australia and work with Bourne and Associates at an international level including the United Nations, so peoples globally may benefit.
- Champion (including media campaign) to change the mindset and attitudes towards older citizens - recognise them as equal regardless of age, ethnicity, language, religion, gender, sexual orientation, health or socio-economic status with each having their own unique identity.
- Improve the level and range of education and training programs in the care of the elderly.
- Foster medical practice and treatments that meets each individual's needs; ie not the needs of organisations, or family environments in which they live.
- Change medical and legal systems concerning privacy and informed consent ie when a person does not have capacity/ has capacity.
- Change regulatory arrangements particularly Enduring Powers of Attorney and Guardianship ie "who guards the guardian"?
- Communication inventory. Implement a system controlled by a regulatory framework in which care of the elderly is delivered to meet each person's needs, wants and desires ie individual and communal spaces in aged care facilities/nursing and their own homes and related policies, systems and operations.
- Change the 'Right of Internment' as advanced in this paper.

Photo: www.google.com.au/ search?q=free,+open+book& biw=1061&bih=1131&tbm=isch &tbo=u&source=univ&sa=X&ved =0CCcQ7AlqFQoTCLOjy8mn3M cCFUQZpgodYuUH6Q&dpr=1

13 Sources

ABUEL (2010). Abuse of Elderly in Europe, Documents. Retrieved July, 2010, from http://www.abuel.org/documents.html

Aged and Community Care Victoria (2010). Aged and Community Care Victoria. Retrieved July, 2010, from www.accv.com.au

Aged Care Branch (2009). With respect to age2009. Victorian Government practice guidelines for health services and community agencies for the prevention of elder abuse. Melbourne: Victorian Government Department of Human Services.

All Types Of Antipsychotic Drugs Increase The Risk Of Stroke, Study Finds (Sept 2008). British Medical Journal. Retrieved: Aug 2015. www.sciencedaily.com/releases/2008/08/080828220511.htm

Allen, P. (2010). RSA Comment: Elder care needs to be the 'new health' Retrieved June 2010, from http://comment.rsablogs.org.uk/2010/06/11/elder-care-health/

Antipsychotic Drugs Hasten Death In Dementia Patients. Retrieved: July 2015 from http://www.forbes.com/sites/cjarlotta/2015/03/19/antipsychotic-drugs-hasten-death-in-dementia-patients/

Antipsychotics May Be Deadlier Than Thought for Dementia Patients. Retrieved: July 2015 from http://consumer.healthday.com/cognitive-health-information-26/alzheimer-s-news-20/antipsychotics-may-be-deadlier-than-thought-for-dementia-patients-697530.html

Antipsychotics, Other Psychotropics, and the Risk of Death in Patients With Dementia Number Needed to Harm. Retrieved: July 2015 from http://archpsyc.jamanetwork.com/article.aspx?articleid=2203833

Antipsychotic Use in Elders With Alzheimer's Leads to Large Increase in Mortality. (Source: The Lancet). Retrieved: 2010 from http://www.docguide.com/antipsychotic-use-elders-alzheimers-leads-large-increase-mortality

Australian Commission on Safety and Quality in Health Care (2008). *About the Australian Charter of Healthcare Rights: A guide for patients, consumers, carers and families.*Retrieved: August, 2010, from http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ACHR

Australian Government Productivity Commission (2010). Caring for Older Australian, Productivity Commission Issues Paper. Canberra: Australian Government Productivity Commission, Commonwealth of Australia.

Ballard, C., Hanney, M. L., Theodoulou, M., McShane, R., Kossakowski, K., Gill, R., Juszczak, E., Jacoby, R. (2009) *The dementia antipsychotic withdrawal trial (DART.-AD): long-term follow-up of a randomised placebo-controlled trial.* The Lancet Neurology, 8 (2), 2009, 151–157.

Ballard, C., Creese, B., Corbett, A. & Aarsland, D (2011). Atypical antipsychotics for the treatment of behavioral and psychological symptoms in dementia, with a particular focus on longer term outcomes and mortality. Expert Opinion on Drug Safety, 10(1), 35-43.

Banerjee, S. (2009). The use of antipsychotic medication for people with dementia: time for action. A report for the Minister of State for Care Services. Department of Health, United Kingdom.

Beckett, A. (2009, 22-23 October 2009). Victorian Government practice guidelines for health services and community agencies for the prevention of elder abuse. Paper presented at the With Respect to Age - 2009: Ageing Safely Forum. Working across sectors to prevent violence & abuse of older people. Adelaide: South Australia.

Commonwealth of Australia Constitution Act July 1900. (1900).

Department of Health and Ageing (2009). *Psychogeriatric Care Expert Reference Group*. Retrieved July, 2010, from http://www.health.gov.au/internet/main/publishing.nsf/Content/CE5FB8607DD06538CA2576020020DD8B/\$File/PCRefGroup.pdf

Dong, X.Q. (2015) *Elder Abuse: Systematic Review and Implications for Practice.* American Geriatrics Society, 63, 1214–1238.

GAO Report Urges Fewer Antipsychotic Drugs For Dementia Patients. Retrieved: July 2015 from http://www.npr.org/sections/health-shots/2015/03/02/390245017/gao-report-urges-fewer-antipyschotic-drugs-for-dementia-patients

Healthy diet could cut risk of Alzheimer's disease. http://www.ncbi.nlm.nih.gov/pubmedhealth/behindtheheadlines/news/2015-03-31-healthy-diet-could-cut-risk-of-alzheimers-disease/

Huybrechts, K. F., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, J., Lucas, J. A. & Schneeweiss, S. (2012). *Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population cohort study.* British Journal of Medicine, 344, e977.

NSW Ministry of Health. (2013). Assessment and management of people with behavioural and psychological symptoms of dementia: a handbook for NSW clinicians. http://www.health.nsw.gov.au/ dementia/Publications/assessment-mgmt-people-bpsd. pdf

Office of the United Nations High Commissioner for Human Rights (1991). *Principles for the protection of persons with mental illness and the improvement of mental health care*. United Nations, General Assembly Resolution 46/119.

O'Neill N, Peisah C (2011) Capacity and the law. SydUPLawbk1 (Sydney University Press). http://www.austlii.edu.au/au/journals/SydUPLawBk/2011/1.html

Scholzel-Dorenbos, C. J., Meeuwsen, E. J., & Olde Rikkert, M. G. (2010). *Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia*. Aging Ment Health,14 (1), 113-119.

Steinberg, M., Lyketsos, C. G. (2012) Atypical Antipsychotic Use in Patients With Dementia: Managing Safety Concerns. Retrieved: Aug 2015. http://dx.doi.org/10.1176/appi.ajp.2012.12030342

The Victorian Law Reforn Commission's *Guardianship: Final report* (18 April 2012). Retrieved: July 2015. www.lawreform.vic.gov.au/projects/guardianship-final-report#.dpuf

The Use of Restraints and Psychotropic Medications in People with Dementia. (2014) Alzheimer's Australia Inc.

The 2014 World Cancer Congress will take place in Melbourne, Australia on 3-6 December 2014. www.worldcancercongress.org/melbourne-2014

Van Marum, R. J., Jansen, P. A. F., Souverein, P. C., Alfred F. A. M. Schobben, A.F. M., Egberts, A. C. G. (2008) *Antipsychotic Drug Use and Risk of Pneumonia in Elderly People*. Journal of the American Geriatrics Society, 56 (4), 661–666.

Victorian Equal Opportunity & Human Rights Commission (2009). *The Victorian Charter of Human Rights and Responsibilities*. Retrieved June, 2010, from http://www.humanrightscommission.vic.gov.au/human%20rights/the%20victorian%20charter%20of%20human%20rights%20and%20responsibilities/

Ward, W. E., & Ashaye, K. A. (2008). An observational study of the needs and quality of life amongst patients in the treatment of Alzheimer's dementia with cholinesterase inhibitors. Curr Aging Sci, 1 (2), 140-143.

World Health Organisation (2010). *International Classification of Functioning, Disability and Health (ICF)*. Retrieved July, 2010, from http://www.who.int/classifications/icf/en/

14 Attachments

About the Authors

Michael and Carolynne Bourne AM

Focused investigations across a range of sources - books, articles, reports, web-based documents, discussions with health professionals, carers, government agencies, peak bodies, those involved directly in the care of the elderly, as well as drawing upon personal experiences have resulted in coauthoring *Eat Bananas. Identity Abuse in the Care of Older Australians*. Bourne and Associates, 2010, submission to the Productivity Commission, Care of Older Australians.

Since then Michael and Carolynne Bourne are committed to championing human rights:

working to promote and protect the rights and well-being of those who can no longer speak for themselves such as those who are elderly, and those who suffer from illness such as Alzheimer's Disease and dementia.

Please see next pages for bios.

Carolynne Bourne AM



Qualifications

B A (Hons), University of Melb, 1987 Dip Art (Graphic design), Swinburne Institute of Technology, 1979

Grad Dip Ed Hawthorn Institute Education, 1988

Post Grad Cert Enterprise Management, Swinburne University of Tech

Industry Training Development Program OSTB, Vic Govt, 1990

Further education includes:

Project Management Models Edward de Bono's School of Thinking **Monash University** Radioactive Usage. Storage. Disposal • Health and Safety

RMIT Scanning Electron Microscopy
Transmission Electron Microscopy

Australian Institute of Management Lateral Thinking and Problem Solving • Negotiation Skills • Interviewing Skills • Stress Management • Presentation

Melbourne Museum Masterclass Design: Milan

Melbourne University Computers in Learning Laboratories

Some current and past affiliations and memberships

Member of the Order of Australia (AM) · Patron, Architectural Glass Design Association • Member, Committee for the Economic Development of Australia (CEDA) • Member, CEDA "CEO Roundtable" • Fellow Royal Society of the Arts, UK Member, Built Environment **Design Professions Action** Agenda, Manufacturing, Engineering and Construction, Department of Industry Tourism and Resources, Australian Government • Member, National Centre for Sustainability Advisory Board, Swinburne University of Technology • Member, Master Builders Association of NSW, Training Committee • Member, Victorian Design Advisory Board, Victorian Government Member, Department of Premier and Cabinet, Victorian Design Industry Workshop • Design Strategy Reference Group (Policy), Victorian Government • Member, Task Group, Creative Australia Project, Commission for the Future • Member. Australian Academy of Design Member, Federal Government's Action Agenda: Furnishing Industry, Innovation and Design Committee • Member, Artisans Guild of Australia (Hon) • Board Member, Artists and Industry P/L • Member, the National Trust Cemeteries Committee • Member, Australian Society of Authors

Carolynne is an entrepreneur and alternative thinker who brings significant local, and international experience in medical laboratory science, business, consumer psychology, research, design and education to the challenge of bridging the gap between turning ideas into practical, commercial, innovative solutions, as well as human rights (see previous page).

Alternative Thinking

Carolynne's work fuses business+consumer psychology+research+multidisciplinary design/production+technology - an holistic approach to meet end-users needs, wants and desires. In the process, she uses new ways of thinking, new ways of working to create value for owners, shareholders, clients/customers/patients, employees and importantly, the communities in which the organisation operates.

Alternative thinking is underpinned by Research - a diagnostic and forensic approach is required to determine the human element in providing goods and services to meet our needs, wants and desires.

Background

Carolynne joined Nylex as an industrial chemist. She subsequently took up a position at Monash University as a clinical and research medical laboratory scientist, then the position she also held at the Alfred Hospital for five years before returning to Monash University to take up the position of Chief Technical Officer (Genetic Engineering). In addition, to her work in science and design, she has established her own businesses.

In 1990 she joined a project which was to ultimately develop into International Specialised Skills Institute where she held the position of founding CEO until 2010 with Sir James Gobbo AC, CVO, the founding Chairman who initiated the project. Under Carolynne's leadership, the ISS Institute established itself as a unique resource focusing on 'skill deficiencies' ie capabilities (skills/know-ledge/insights) that are not available through accredited Australian higher education institutions across industry sectors. She resigned this position to spend precious time with her mother who had Alzheimer's Disease and has now passed away; thereafter, she set-up Bourne and Associates P/L (B&A).

She has been conferred the position of Adjunct Senior Research Fellow, Swinburne University.

Publications

Carolynne has numerous articles and papers published in Australia and internationally including Lancet.

She has accepted the invitation to sit on the Editorial Advisory Board of the new international publication, "The Journal of Design, Economics, and Innovation".

Award

In 2006 Carolynne was deeply honoured with a Member of the Order of Australia (AM).



Qualifications

Full member of the Australian Psychological Society

Member of the College of Educational and Developmental Psychologists

Registered as an Educational Psychologist with the Psychology Board of Australia

M EducationMelbourne University
(by major thesis)

M Education Admin Melbourne University Units completed: Change Processes Policy and Planning Organisational Theory

B ArtsUniversity of Melbourne

B EducationUniversity of Melbourne

Post Graduate Diploma Criminology University of Melbourne

Trained Primary
Teachers Certificate
SCV Frankston

Michael Bourne

In 2010 Michael Bourne established Bourne and Associates P/L.

As its cofounder and Director, he brings significant experience as a highly respected practising psychologist, researcher, businessman, and educator to the challenge of bridging the gap between ideas, problems to solutions. A significant proportion of his professional service has been in leadership positions.

Michael is an Education and Developmental Psychologist registered with the Psychology Board of Australia and is a full member of the Australian Psychological Society (MAPS) for over 30 years.

He has spent over 40 years in education having taught and worked in primary and secondary schools and lectured in Consumer Psychology, Marketing and Total Quality Management to students of design and visual merchandising studying at tertiary institutions (Swinburne and RMIT Universities).

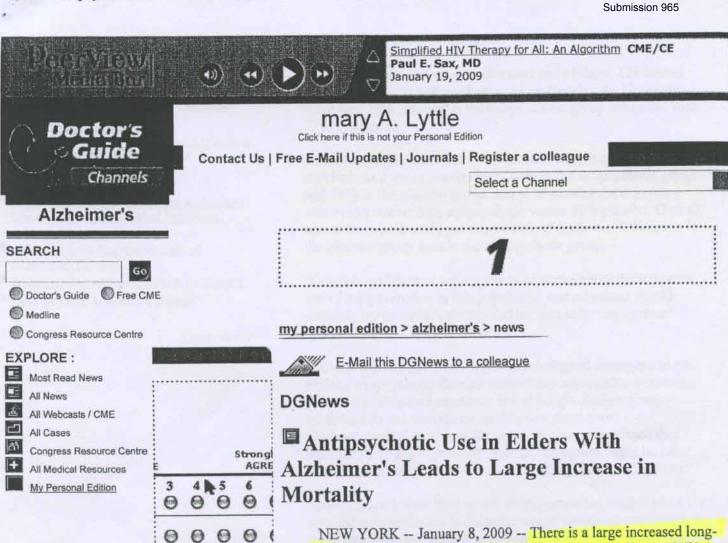
He has continued to support schools with psychological services in most of the Metropolitan area of Melbourne, and a number of schools statewide, in general and senior psychological positions. In addition, he is a leader in high care 'Criticial Incidents' in schools - working with government agencies including police, principals, teachers, students (secondary and primary school levels) and parents.

With work in curriculum and teacher education, he has, held positions on statewide and national testing (assessment) programs; undertaken research projects at Melbourne University and the Australian Council of Educational Research and been a member of the statewide Primary Maths and Curriculum Standing Committees; educational managment at the Reading, Research and Treatment Centre, a statewide specialist centre; worked directly under members of the Ministerial Committee Testing of Literacy and Numeracy, where he managed the Assessment Unit and its programs to professional groups, teachers and parents across Victoria at all levels.

Consultancy projects include proposal presentation to the Victorian Government in the field of lateral thinking with Dr Edward De Bono; visiting expert presenter in International Specialised Skills Institute's industry workshops in Consumer Psychology and a speaker to numerous groups across industry sectors, designers and educationalists. Michael has authored a number of research articles and papers.

He has presented the work through a wide range of activities such as lectures, forums and workshops. In addition to his career in psychology, Michael has also co-owned an antique furniture retail/wholesale business.

He has pursued his interest in the links between health and psychology through his M. Ed. thesis, Educational, Psychological and Demographic Characteristics of Coronary Heart Patients.



Recent news - Alzheimer's

Warning | Privacy

- TopAbstracts in Alzheimer's 01/22/2009 (DGNews)
- Diabetes Associated With Different Types of Brain Injury in Patients With Dementia (DGNews)
- TopAbstracts in Alzheimer's 01/08/2009 (DGNews)
- REM Sleep Disorder May Be Early Sign of Dementia, Parkinson's Disease - (DGNews)

News archive

Recent webcasts/CME - Alzheimer's

- Dementia in Hispanic Americans:
 The Reasons Behind the Risk
- 🖘 Modifiable Risk Factors Underlie Higher Dementia Rates in African Americans
- ■» Beliefs About Dementia Among Hispanics Impede Diagnosis and Treatment

NEW YORK -- January 8, 2009 -- There is a large increased longterm risk of mortality in patients with Alzheimer's disease (AD) who are prescribed antipsychotic medication, according to the long-term follow-up results of the Dementia Antipsychotic Withdrawal Trial (DART-AD) published early online and in the February edition of *The Lancet Neurology*.

While there is evidence of modest short term benefits of antipsychotic treatment for the neuropsychiatric symptoms of AD, there is also clear evidence of an increase in adverse effects.

However, all the data regarding mortality so far relate to short term follow-up of 12 weeks or less.

Clive Ballard, MD, Wolfson Centre for Age-Related Diseases, King's College London, London, United Kingdom, and colleagues have provided the first long-term follow-up data for AD patients given antipsychotic drugs.

Between 2001 and 2004, patients with AD aged 67 to 100 years who resided in facilities in 4 UK areas were randomly assigned to continue with their antipsychotic treatment (thioridazine, chlorpromazine, haloperidol, trifluorperazine, or risperidone) for 12 months or to switch their medication to an oral placebo.

The primary outcome was mortality at 12 months. An additional follow-up telephone assessment was done to establish whether each participant was still alive 24 months after the enrolment of the last participant (range 24-54 months). Causes of death were

Submission 965

eativity and Dementia: Emerging Diagnostic and Treatment Methods for Alzheimer's Disease

Next Steps in Alzheimer's Disease:
Improvements in Diagnosis and Treatment

Webcasts/CME archive

Recent cases - Alzheimer's

- Rapid Cognitive Improvement in Alzheimer's Disease Following Perispinal Etanercept Administration
- Advances in the Pharmacotherapy of Alzheimer's Disease
- Distinguishing Alzheimer's From Parkinson's
- Does He Have Alzheimer's Disease?

Cases archive

obtained from death certificates.

In total, 165 patients were randomised and of these, 128 started treatment -- 64 on antipsychotics, 64 on placebo. At 12 months, there was 70% survival in the antipsychotic group compared with 77% in placebo.

However, longer term follow-up revealed bigger differences in survival. At 2 years, survival was 46% in the antipsychotic group and 71% in the placebo group, and at 36 months the difference was even greater: 30% antipsychotic versus 59% placebo. Overall, across the whole study period, the risk of death was 42% lower in the placebo group than in the antipsychotic group.

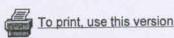
"Our data add further serious safety concerns about the long-term use of antipsychotics in this population, and clinicians should certainly try to replace antipsychotics with safer management approaches," the authors wrote.

"Several studies have shown that psychological management can replace antipsychotic therapy without any appreciable worsening of neuropsychiatric symptoms; and although cholinesterase inhibitors do not seem to be an effective short-term pharmacological treatment for agitation, there is evidence that memantine or antidepressants such as citalopram might be safer and effective alternatives for some neuropsychiatric symptoms."

"Our opinion is that there is still an important but limited place for atypical antipsychotics in the treatment of severe neuropsychiatric manifestations, particularly aggression, of AD," they continued. "However, the accumulating safety concerns, including the substantial increase in long-term mortality, emphasise the urgent need to put an end to unnecessary and prolonged prescribing."

SOURCE: The Lancet Neurology





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Please rate this article	Strongly DISAGREE				Strongly AGREE			
	1	2	3	4	5	6	7	1
	0	0	0	0	0	0	0	- 1

20

