

Guest editorial

Robert Stirling, Project Manager, Network of Alcohol and other Drugs Agencies



Dual diagnosis: caring for people with mental health and drug and alcohol problems

Co-existing mental health and drug and alcohol problems are associated with a range of social and health problems affecting not only the individual but the family, carers and social network of the individual as well. With data indicating that almost one in five Australian adults have been affected by mental health and drug and alcohol problems, it's disappointing that a large number of families and carers supporting those affected, are receiving little to no support themselves.

The families and carers of people with co-existing mental health and drug and alcohol problems experience heightened levels of anxiety and depression and have a higher care-giving burden. Not to mention the shame, stigma and resulting isolation that can be found when supporting someone who has both mental health and drug and alcohol problems. Yet despite the mounting research on the negative impact that these problems have on families and carers, support has been hard to find.

Thankfully in recent years Government have started taking notice and are directing funding to organisations to support families and carers in need.

The Network of Alcohol and other Drugs Agencies (NADA) is the peak body for non-government drug and alcohol services in NSW. In 2008, NSW Health funded NADA to increase the capacity of its member agencies to support the families and carers of people with mental health and substance use problems accessing their services.

Traditionally some services have not wanted to engage with families and carers because they saw them as part of the problem and NADA has been working with its members to shift these attitudes. NADA has been promoting research that proves that an increased role of families and carers in services can assist in getting

people into treatment, improve health related outcomes and reduce the impact and harms for families and carers, including children.

As part of the Family and Carer Project, NADA developed the Tools for Change toolkit which aims to assist services in moving towards a more family inclusive model where all parties are engaged, supported and involved.

Whilst not all services will be in a position to support families and carers, we have encouraged our members to form partnerships with organisations that can provide support so that appropriate referrals are made.

In moving forward, a recent survey indicates that NADA members recognise the important role that families and carers play in the recovery process and with increased support from NADA and Government, will continue to develop their services to ensure that the families and carers of people with co-existing mental health and drug and alcohol problems are supported.

Robert Stirling is Project Manager with the Network of Alcohol and other Drugs Agencies (NADA) - the peak organisation for the non government drug and alcohol services in NSW. NADA supports its members to reduce drug and alcohol related harm to individuals, families and the community. Robert is currently working on projects to increase the capacity of its members to respond to people with co-existing mental health and drug and alcohol problems and their families.

For more information on NADA, the Family and Carer Project or to download a copy of the Tools for Change toolkit please go to www.nada.org.au

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Guest editorial

David McGrath, Director of Mental Health and Drug and Alcohol Programs at NSW Health



NSW Health initiatives for carers of people with drug and alcohol problems and dual diagnosis

People with co-existing drug and alcohol and mental health problems often present with multiple and complex social and health problems. These problems may affect not only the individual, but also their family, friends and broader social network. Families and carers may experience a range of emotions including shame, stigma, and feelings of helplessness and isolation. Families and carers may also develop health problems such as depression, stress and anxiety.

Families and carers have unique expertise, understanding and ability to support a person experiencing a co-existing drug and alcohol and mental health problem. Including families and carers in treatment planning, providing them with accurate information and knowledge, and giving them strategies to address their own health and well being have been shown to improve outcomes for families and carers and consumers.

In recognition of these broader impacts on families and carers and the important role they may play in improving treatment and health outcomes, NSW Health Mental Health and Drug and Alcohol Office (MHDAO) has identified a number of opportunities for the development of specific support services to better cater for their needs. This article outlines some of those key initiatives.

MHDAO funded the development of the 'Tools for Change - A new way of working with families and carers' toolkit, developed by the Network of Alcohol and other Drugs Agencies (NADA) as part of the Mental Health and Drug and Alcohol Family and Carer Project. This toolkit is designed to assist the services of non-government organisations (NGOs) to develop practical strategies to meet the needs of families and carers and to develop more family inclusive practices. In May-June 2009 NADA held four free one day workshops aimed at improving the support offered to families and carers of clients accessing NGO drug and alcohol services. In addition, in order to assist the development and implementation of programs to improve support services for families and carers, a grants program has also been funded by NSW Health through NADA. These grants are designed to assist organisations to develop initiatives or to expand existing strategies to engage and support families and carers.

MHDAO provides funding to Family Drug Support, a 24 hour seven day a week telephone service which offers support, advice, information and referrals to families and friends of drug users. Family Drug Support is operated primarily by volunteers who have experienced first hand the impact of a family members' substance dependency. NSW Health has also revised the 'Family Matters: How to approach drug issues with your family' booklets and disseminated 450,000 copies to parents and carers through direct mail, educational institutions, Community Drug Action teams and libraries. This resource provides practical support and strategies to assist parents to discuss drug and alcohol use.

MHDAO offers a Family and Carer Mental Health Program which provides funding to NGOs and Mental Health Services for the education and training, individual support and advocacy, peer support and participation of families and carers. While support through this program is primarily available for the families and carers of people with a mental illness, the families and carers of people with co-morbidity or dual diagnosis that includes a diagnosis of mental illness, are also able to access it. NSW Health welcomes the opportunity to work collaboratively with carer organisations to better support NSW families and carers.

Editor's note: Carers NSW is one of the NGOs that delivers the Family and Carer Mental Health Program. For more information go to www.carersnsw.asn.au and click on 'Carer support programs'.

David McGrath is the Director of Mental Health and Drug and Alcohol Programs at NSW Health and has been in this role for almost four years. With a background in psychology, 15 years clinical experience, and a masters degree in business he has a mix of skills that are appropriate for managing the complex NSW Mental Health and Drug and Alcohol programs. David is on the NSW Psychologists Registration Board as well as being the incoming Chair of the Intergovernmental Committee on Drugs, and has represented Australia at the United Nations Commission on Narcotic Drugs.

For more information on the NSW Health Mental Health and Drug and Alcohol Office (MHDAO) go to www.health.nsw.gov.au/mentalhealth/index.asp

Carers Week

This year Carers Week takes place from 18-24 October and the theme is 'Anyone Anytime'. One hundred and ninety eight grants have now been provided for carer support groups and organisations to hold carers week activities around the state. These grants have been funded by the NSW Department of Ageing, Disability and Home Care. For an outline of these events, see the insert.

In addition, Carers NSW is partnering with Babana Aboriginal Men's Group Inc, the City of Sydney and a range of service providers (government and non-government) to hold a Carers Day Out event in Sydney Square on Tuesday 20 October. Located between Sydney Town Hall and the St Andrews Cathedral, the square is a central location, with ready access to public transport. On the day there will be information stalls, with information and free goodies available. There will also be a range of performers and speakers taking to the stage. Carers and the general public are invited to attend between 10am and 2pm to take part in what will no doubt be a festive day!

Our regional offices are also participating in a number of Carers Week events. For a full list of events happening for Carers Week go to www.carersweek.com.au

AGM

This year's Annual General Meeting will be held on 26 November 2009.

The AGM includes the presentation of yearly reports by the CEO and Board, and is followed by the annual Clare Stevenson Lecture, which this year will be delivered by Ms Caroline Jones, renowned broadcaster and author of *Through a Glass Darkly: A journey of love and grief with my father* (see page 10).

Please see the inserts for more detailed information on the AGM and the Call for Nominations.



Logie award winning journalist Caroline Jones

Young Endeavour

In June / July, young carer Richard Liggins won the opportunity to take part in 10 days sailing on the Young Endeavour ship. Thanks to the sponsorship of Rothschild Australia, Richard, 16, boarded the boat with other young crew and staff.

On the 48 foot ship, Richard got the chance to learn to sail, while meeting other young people and seeing the East Coast of Australia and the wildlife that inhabits it. Games and team-building exercises also helped the crew to bond on what is a unique adventure for those who experienced it. "I definitely learnt heaps," says Richard. "I have a bigger mind and feel more confident about myself and the future. It was a real load off to be amongst people that didn't know me for a while. I also made progress in conquering my fear of open water, by diving into the water from the ship."

Richard is the second young carer to be selected through Carers NSW to take a place on the Young Endeavour, thanks to Rothschild.



Richard finding his sea legs

The Not-For-Profit Board: What is its Role? Is it Different from a Corporate Board?



Laraine Toms,
President of Carers NSW

Not-For-Profit (NFP) board members are often asked what they actually do. There is also some uncertainty about how an NFP board differs from a corporate board, if at all. As the election for Carers NSW board members is coming up I thought it would be a good idea to talk in this issue about the roles and responsibilities of NFP boards.

Carers NSW board members, or directors, are volunteers. This is a major difference between our directors and directors of corporate, or commercial, boards who are paid.

Carers NSW directors are elected by the members of the organisation, corporate directors are not.

Importantly, there is no difference between NFP directors and corporate directors in their responsibilities or liabilities as a director. Being a volunteer director makes no difference to the fiduciary duty of our directors.

To understand the role of any board, it is important to differentiate between management and governance. The board does not manage the staff or day to day operation of the organisation. That is the role of the Chief Executive Officer (CEO). The board is responsible for governance. Essentially, modern governance means ensuring that all accountability safeguards are in place. It is the board which is ultimately responsible for the organisation and its activities. These include employing the CEO, adhering to relevant government legislations, overseeing the management and reporting of the organisation's finances, and being accountable and reporting to its many stakeholders, including members and funders.

Directors also provide the organisation with guidance and support and are the guardians of the organisation's vision and mission. The board needs to make sure that the organisation acts according to its stated mission/vision and mission/goals and for the purpose for which it receives tax exemption.

In addition, it is a board's responsibility to:

- **Establish a clear vision and mission**
What the organisation plans to achieve, where it wants to be and how it plans to get there
- **Identify the organisation's core values**
- **Be strategic in determining the organisation's programs and services**

- **Provide financial oversight and ensure the organisation meets its legal and financial requirements**

Guiding/managing/facilitating the development of budgets, monitoring program activities by tracking key performance indicators, managing investments, and reviewing financial statements

- **Develop appropriate risk management practices**
Ensure an understanding of the risks the organisation faces and its ability to obtain insurance for some of those risks and taking action to avoid or mitigate other risks

- **Be ethical**

Just as corporate or commercial boards have a responsibility to their shareholders for ethical and wise financial management, not-for-profit boards are responsible to their members, funders and private donors. All transactions – financial or otherwise – need to be transparent with a consistency of approach and purpose

- **Build and sustain government relations**

Carers NSW does not belong to, or support, any political party. Board members advocate for carers to all politicians and brief government officials about the key issues facing carers.

The Board and the CEO

The board works closely with the CEO to further the organisation's goals and to broaden its financial and membership support base. Together they regularly review the organisation's overall operation, vision and mission and program goals and decide on a regular evaluation process for all programs to monitor their effectiveness.

NFP and corporate/commercial boards alike carry the trust and expectations of their stakeholders. The Board of Directors of Carers NSW are committed to good governance and support of carers, in all their diversity, across NSW.

2000 Companion Cards issued in NSW

More than 2000 Companion Cards have now been issued in NSW since the card was introduced at the end of March 2009 by the NSW Government.

The Companion Card allows people with a profound or severe disability to take their carers on public transport and to events for free.

About 450 businesses have signed up to offer benefits for Companion Card holders.

The card is also recognised by NSW Government-operated services and facilities like public transport and the Sydney Opera House.

The Card is managed by National Disability Services (NDS), the peak body for disability services.

Eligible people should contact the Companion Card information line on **1800 893 044** to obtain an application form.

AIHW report on frequency of multiple disabilities

In its latest report on disability in Australia, The Australian Institute of Health and Welfare examines the frequency of multiple disabilities and their impact on the care needs of Australians.

The report, *Disability in Australia: multiple disabilities and need for assistance* shows that in 2003, half of all Australians with disability, or about 2 million people, had a combination of two or more disabilities.

These disabilities can include intellectual, psychiatric, sensory/speech, disability from acquired brain injury (ABI) and physical disabilities.

More than half of people aged 15 to 44 with ABI (more than 85,000 people) or intellectual disability (over 95,000 people) had three or more disabilities.

Significantly, the report also shows a substantial proportion of care for people with multiple disabilities is provided by family members and friends.

Dr Xingyan Wen of the Institute's Functioning and Disability Unit said: "The more disabilities people had, the more likely they were to need help with 'core' daily activities such as self care, mobility and communication."

To read the report, go to www.aihw.gov.au/publications/index.cfm/title/10788

Pension increase

This increase includes the rise announced in the May Budget, as part of the Australian Government's Secure and Sustainable Pension Reform, plus regular indexation.

Single pensioners on the maximum rate of the pension will receive:

- An increase of \$60 per fortnight (\$30 a week) in the base pension
- An increase of \$5.00 per fortnight (\$2.50 a week) in the new Pension Supplement
- Indexation increases of \$5.50 per fortnight in the base pension and \$0.33 per fortnight in the Pension Supplement.

Couple pensioners combined on the maximum rate of the pension will receive:

- An increase of \$20.30 per fortnight (\$10.15 a week) in the new Pension Supplement
- Indexation increases of \$9.20 per fortnight in the base pension and \$0.43 per fortnight in the Pension Supplement.

The Pension Supplement replaces, and incorporates the full value of the Utilities Allowance, Telephone Allowance (at the higher internet rate), the GST Supplement and the Pharmaceutical Allowance.

Full details of the changes to rates and thresholds are available at www.jennymacklin.fahcsia.gov.au/internet/jennymacklin.nsf/content/index_table_200909.htm

Dementia on the rise

A new Alzheimer's Australia report indicates the prevalence of dementia will increase from 245,400 people in 2009 to around 1.13 million people by 2050.

These figures are a dramatic increase from previous projections released in 2005.

This rise is due to increases in the projections in the ageing population by the Australian Bureau of Statistics and increases reported by epidemiologists in the expected number of people with dementia in older age groups.

NSW specific data is included, and there is a focus on CALD and ATSI populations and the need for appropriate research and support for people with dementia, their families and their carers.

In the report, Access Economics has warned that future growth in the number of people with dementia will have substantial consequences for the already pressured Australian health care system and the quality of life of Australians.

To read the report go to www.alzheimers.org.au

New dementia resources

The Department of Health and Ageing, under the Australian Government Dementia Initiative, have funded the development of a suite of training resources about 'how the environment, technology and you' can help a person living with dementia.

Resources available include:

- 33 help sheets
- a DVD with facilitator's guide
- a home safety checklist
- a poster book
- a promotional brochure and poster
- a website with virtual tour and on-line resources

These resources are available for people with dementia, carers, dementia care workers, health professionals and service providers including those from culturally and linguistically diverse backgrounds, those living in rural and remote communities and younger people with dementia.

Copies of these free resources can be ordered by emailing dementia@health.gov

New report on barriers faced by people with disabilities and their families in Australia

The National People with Disabilities and Carer Council have released a report examining the barriers faced by people with disability.

Shut Out: The Experience of People with Disabilities and their Families in Australia is the culmination of thousands of views expressed through submissions, forums and focus groups across Australia, and was commissioned by the Australian Government to inform the National Disability Strategy.

Parliamentary Secretary for Disability Bill Shorten said that more than 2,500 people attended the public consultations and over 750 submissions were received.

The Australian Government is providing more than \$5 billion to the states and territories over the next five years through the National Disability Agreement to provide specialist disability services, including respite, supported accommodation and early intervention.

To find out more information on the report or to obtain a copy go to www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx

Nutrition and health tips for time-poor carers

Sharon Trainor,
nutritionist and former carer

I would like to share a little of my journey as a carer and provide some tips, both from a carer and nutritionist's perspective, on how we can improve and maintain better health, whilst caring for a loved one.

In 1996 my husband, then 49 years of age, was diagnosed with an inoperable brain tumour. Bernie was given three to six months to live at that time, but was fortunate to survive for another 10 years after his initial diagnosis. This, in part, I attribute to an extremely healthy diet as well as meditation, positive thinking, strong spiritual belief, love and support.

Unfortunately over this 10 year period we were to experience a tremendously emotional and traumatic time. Bernie was to eventually lose his ability to hear and communicate, suffer severe epilepsy and finally, paralysis. Our lounge room became a hospital ward and I was flung into the role of nurse/carer/wife.

Carers are often in situations where there are heavy physical demands on them in caring for the patient. In these circumstances, their diet may be poor or inadequate which may lead to a loss of general fitness due to lack of exercise. The carer is also likely to be getting less sleep.

During my time as a carer, I was always conscious of eating well and preparing nutritious meals, not only for my own health, for Bernie's also. Another important strategy which enabled me to cope better was to have a rest when Bernie was asleep. Sometimes I would go for a quick walk or do some gardening. This didn't always go to plan but was enough to help preserve my sanity.

Some personal survival tips

- Do something that makes you feel good eg: listen to music, make a pot of tea and take the time to sit and drink it
- Recognise the tasks you can ignore and use this time to have a break
- Remember you're not super human and not expected to cope all of the time
- Keep in contact with people that make you feel good and remember to laugh
- Take advantage of help that friends and other family members may offer no matter how small
- Ask a family/friend to pick up some groceries for you, mow the lawn or pay some bills to save you time
- If you are caring for someone in your home, you might suggest to your friends that they sit with the ill person while you run some errands, or even look after other things in the home
- Remember that the person you are caring for is equally frustrated and try to spend some quality, relaxed time together
- Exercise when you can to help reduce your stress levels and improve your health.

Budget and time friendly ideas to maintain good nutrition

- Plan meals that don't require too much preparation such as stir fries, steamed vegetables and grilled fish/meat/chicken, pasta
- Always keep some frozen crumbed fish (heart tick), oven baked fish (heart tick) on hand
- Buy what is in season and look for weekly specials
- Always keep tinned tuna or salmon in your pantry. This may be used for sandwiches, tuna on crackers, macaroni/pasta dishes or salmon/tuna patties
- Cook extra and freeze leftovers such as casseroles, pasta
- Cook a pot of soup and throw lots of vegetables/beans in for a good, cheap hearty meal with some fresh bread
- Buy cheaper, lean cuts of meat such as shin beef, which are great for soups or casseroles
- Pikelets are always cheap, easy and filling for a snack
- Try to eat fresh fruit and vegetables daily
- Avoid eating deep fried and takeaway foods too often
- Don't drink too much caffeine or drink excess alcohol as this will only make you feel worse and lessen your ability to cope
- Take a multivitamin every day to help balance the energy you're burning up
- Have a treat!





National Health and Hospitals Reform Commission Final Report – what does it mean for carers?

Elena Katrakis, CEO, Carers NSW with reference to the Carers Australia summary of the report – *'Invisible' carers come into focus*

In early 2008, the Prime Minister and the Minister for Health and Ageing announced the establishment of the National Health and Hospitals Reform Commission (NHHRC) to look at reforming Australia's health system. The NHHRC then underwent a consultation process involving submissions, forums and meetings looking at the future architecture of Australia's Health System. The result was the NHHRC interim report released in February 2009 and the final report on 27 July 2009.

Carers NSW was actively involved in the consultation process, campaigning for acknowledgement of the role carers play in the health system and better health and wellbeing for carers.

Now the final report has been released, it is clear to see there has been a shift in the overall thinking about the role carers play in the health system. This is evident through some of the recommendations, that specifically reference carers (outlined in the Carers Australia summary of the report).

The role of carers in the health system Recommendation 14

We acknowledge the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty. We recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications. We also recommend improved access to respite care arrangements to assist carers sustain their role over time and that the health of carers should also be a priority of primary health care services dealing with people with chronic conditions.

Recommendation 14 is included as part of a series of recommendations under the heading 'Taking Responsibility'.

Consideration for those in rural and remote areas

Recommendation 67

We recommend that a patient travel and accommodation assistance scheme be funded at a level that takes better account of the out-of-pocket

costs of patients and their families and facilitates timely treatment and care.

Recommendation 67 is included under the heading of 'Facing Inequities: Delivering better health outcomes for remote and rural communities'.

Caring and mental health Recommendation 82

We acknowledge the important role of carers in supporting people living with mental disorders. We recommend that there must be more effective mechanisms for consumer and carer participation and feedback to shape programs and service delivery.

This recommendation reflects a central theme present in the design principles, suggesting that services must present carers with the ability to provide feedback on service delivery.

Other important recommendations that may not reference carers directly, but outline some of the issues carers, or society at large, face in relation to caring are:

Increased need for care

More people will be frail and seeking assistance from informal carers, yet they will be busier than ever earning a living to meet rising costs of living and their own retirement needs. For each older person in 2007, there were five working-age people, while in 2056 there will be fewer than three working-age people for every older person.

Carers in the 'service maze'

All Australians suffering from chronic illness require a range of health services delivered by a variety of health professionals across the spectrum of primary,

secondary and tertiary health care. Navigation through the health system for a person with chronic disease is complex. People often fall between the 'care gaps' and 'handovers' between care givers.

Self-management and partnerships with carers

We must be active participants in our own good health, working in partnership with our health professionals, our carers and families. But this has to occur within the context of our social and economic circumstances and the communities in which we live. The aim has to be to encourage and support everyone to achieve their maximum health potential, regardless of their age or whether they have a chronic illness or a disability.

Meeting health needs over the life course

The health and aged care system should be able to meet the entire range of people's health needs over their life course. Meeting those needs requires a system to be built on a foundation of strong primary health care services with timely access to all other health and aged care services organised to promote continuity of care and good communication across the various health and aged care professionals.

This is just a sample of how the report relates to carers. To read the full report go to www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report. To read Carers Australia's analysis on how the report relates to carers, go to www.carersnsw.asn.au

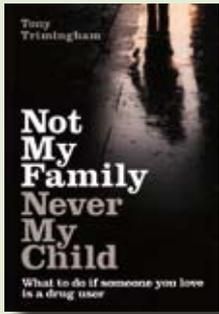
Carers NSW Policy team update

The beginning of this financial year has been an active and busy time for the policy team. Our activities for this period include:

- An evaluation of Home and Community Care (HACC) services for carers in the Metro North Region on behalf of the NSW Department of Ageing, Disability and Home Care
- Finalisation of the Carers NSW 2008 Survey Report
- A submission on behalf of the Carers Associations National Policy Working Group to the Inquiry into the Harmonisation of Disability Parking Permit Schemes in Australia
- Submission to the NSW Substitute decision-making for people lacking capacity Inquiry
- Coordination of the Strategic Carers Action Network (SCAN) Meeting and Seminar Series
- Presentation at the Home and Community Care and Community Care Conference - *Connecting our Community*
- Finalisation of the Koori Yarning Resource Manual
- Development of a full statistical profile on Aboriginal carers in NSW
- Development of a draft discussion paper on consumer-directed care (CDC)
- Organisation of 'Working effectively with interpreters' training session for Carers NSW carer support officers
- Promotion of the Carers NSW resources to Hindi and Tamil speaking communities at the Indian-Australian Friendship Fair 2009

- Systemic advocacy of the Program of Appliances for Disabled People (PADP) Inquiry recommendations
- Participation in the national Carers Associations workshop with Australian Government Department of Health and Ageing and consultants developing the revised Carers Eligibility Needs Assessment tool
- Participation in nationally-funded regional consultations coordinated by Commonwealth Respite and Carelink Centres to identify gaps and barriers to services and to provide policy advice to the Australian Government Department of Health and Ageing
- Acceptance of Carers NSW abstract for the 6th National Australian Women's Health Conference to be held May 2010
- Summaries of recently published reports relevant to carers.

To have your say on health, go to www.yourhealth.gov.au. Operated by the Australian Government Department of Health and Ageing, the site has been designed as an engagement and consultation tool to help enable Australians to provide their views to Government on how to improve the health system. The site also provides a calendar of consultation events happening around the country.



Not My Family Never My Child

Tony Trimmingham Review by Laraine Toms, President, Carers NSW

Tony Trimmingham is well known to Sydneysiders as a passionate advocate for families and carers of people who are drug users. Tony's experience of living with son Damien, who died from an overdose of heroin in 1997, and the lessons learned from his own journey and that of other families, was the driving force behind his establishment of the Damien Trimmingham Foundation. The Foundation's working project, Family Drug Support, is a support and education organisation for families of drug users.

This is a powerful and confronting book. It is not just a story but rather it is a complete guide for families and drug users themselves. It is a handbook for making one's way through the journey of drug dependence as a parent, sibling or loved one of a drug user. There is a depth of compassion and understanding that is real and riveting. Tony provides practical advice to people who have their lives turned upside down and who can't begin to see a way forward.

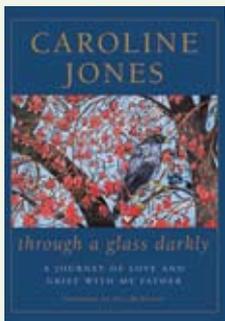
The range of tips, advice, 'strategic hints' as Tony calls them, packed in the book, is broad and based in real experience. There is detailed information on warning signs, early intervention, coping – Tony's Stages of Change and Stepping Stones to Success model – and survival strategies. You will find treatment options and where to go for additional advice and support.

Above all this is a positive book that will instil hope in families and provide real tools to make a difference.

Published by Allen and Unwin, available from bookstores, \$24.95

Through a Glass Darkly: A journey of love and grief with my father

Caroline Jones



After years of telling other people's stories through the ABC program *Australian Story*, Caroline Jones has turned the spotlight on her own life in this very personal exploration of grief.

Through a Glass Darkly is a record of Caroline Jones' personal journey as she watched her beloved 93 year old father suffer and eventually die after heart surgery.

Jones was surprised by the intense grief she felt after her father's death, and the length it lasted.

"I've been given the wisdom of so many people's stories, their real life struggles; I have committed them to memory and treasured them in my heart. And I suppose that is why I am expected not to grieve or even recover quickly from my loss," Jones says in an early diary entry in *Through a Glass Darkly*.

The book interweaves Jones' journal entries with excerpts from her father's own compellingly written reminiscences. This, combined with a selection of family photographs, allows the reader to feel personally acquainted with both Caroline, and her father Brian. The result is a rich record of the love between a father and daughter, the grief that accompanies the unstoppable change to that relationship, and the period of growth and reflection that follows.

This book is highly moving, and acknowledges the intensity of grief that comes when a loved one dies and the caring role is relinquished. It will be welcomed by those who presently mourn the loss or face the imminent death of a family member or friend.

Published by ABC Books, available from bookstores, \$35.00

Tony Trimmingham has donated a copy of his book to a *Carers News* reader. To win the FREE copy, send your name and address to Carers NSW by email to contact@carersnsw.asn.au or to the Librarian, Carers NSW, PO Box 20156, World Square, NSW 2002 by 4 November 2009. The winner will be announced in the next *Carers News*.

Winner of the book *Leading a Support Group: A Practical Guide*, by Keith Nichols and John Jenkins is Yvonne Quadros from Coffs Harbour.

Write to us!

Carers News wants to hear from you. Write us 100 words or less and tell us what you think about the newsletter or issues covered in the newsletter and how they affect you as a carer.

Suggestions also welcomed. Write to ninao@carersnsw.asn.au with 'Attention Editor' in the subject line or write to The Editor, *Carers News*, Carers NSW, PO Box 20156, World Square, NSW 2002.



Project Guardian

**Felicity Dillon, solicitor, Clarendene Estate Planning Lawyers
– a business unit of PricewaterhouseCoopers**

Project Guardian – estate planning for families who have relatives with disabilities – was recently launched in Sydney by Felicity Dillon a member of the specialist estate planning team at PricewaterhouseCoopers.

The intention of the project is to provide best practice estate planning solutions to people who wish to plan for the care of their relatives who have disabilities, as well as protecting and preserving wealth for themselves and their families.

Project Guardian came about through Felicity's involvement as a member of a Personal Network established for a young man in Perth – Paul Jay.

"It was at a BBQ about four years ago that I first met Paul and it wasn't something I thought much about at the time," says Felicity.

"It started with a conversation with his Mum and Dad about establishing a network for him where friends and family could contribute to and expand his social networks. From that meeting a whole series of events occurred culminating in Paul travelling to Sydney for the launch of Project Guardian. That in itself was miraculous.

"Meeting Paul wasn't something that I thought would have such an amazing effect on my life and my career. As a lawyer I now specialise in creating long term sustainable futures for families and this work is incredibly rewarding and fulfilling."

So how can estate planning protect your family?

Estate planning is not just creating a simple Will. It involves structuring your affairs during your lifetime to protect your assets, minimise tax, make provisions for your own incapacity and on your death to have effective structures and strategies in place to pass wealth securely and tax effectively to intended beneficiaries sensitive to their needs, wants and circumstances.



Most simple Wills provide gifts of money and property to family members to be distributed to them by inexperienced executors. Often the impact of providing these gifts is not well understood and family members may end up being disadvantaged rather than benefiting.

Of particular concern are gifts made to family members who have a disability by well meaning relatives often creating an impact on them that is more severe than gifts left to their siblings. These impacts include relatives with disabilities potentially having to establish bank accounts and other facilities beyond their capacities, losing their entitlements to social security benefits and having to pay substantial amounts of tax.

With specialist advice it is possible to structure your affairs, including your Will, to provide an inheritance for your family member with a disability which attracts tax and social security concessions. The use of testamentary and/ or support trusts is the most effective strategy for creating these structures.

It is obviously very important to have a Will but having a simple one may not be enough. Those left to care for more vulnerable relatives will really appreciate the time and care you take to establish sustainable financial structures in your Will and will be better equipped to get on with the most important issue – the loving care of your relative.

*This article is intended to be for information purposes only. It is not legal advice. If you would like more information about Project Guardian, Felicity Dillon can be contacted on **02 8266 9516** or felicity.dillon@au.pwc.com or contact Donal Griffin on **02 8266 8537** or donal.griffin@au.pwc.com*

Clarendene Estate Planning Lawyers – a business unit of PricewaterhouseCoopers

Carers NSW picks up NSW Multicultural Health Communication Award

Multicultural Health Week was held between 27 July and 2 August 2009 to raise the awareness of the various CALD communities across NSW and the state wide health services available to them.

During this week the NSW Multicultural Health Communication Awards were held. The Awards recognise the production of multilingual health resources and, specifically, the effectiveness of the resource, the quality of the translations, the potential benefits for members of the CALD communities they have been produced for and with the judges also taking into account the effectiveness of their distribution.



Mr Peter Todaro, Director of NSW Multicultural Health Communication at NSW Health and Maja Frölich, Multicultural Policy and Development Officer, Carers NSW

The 2009 awards were presented in the Jubilee Room of the NSW State Parliament House on Macquarie Street Sydney, on Wednesday 29 July by the President of the Legislative Council, the Honourable Peter Primrose.

Carers NSW received the Certificate of Commendation for 2009 for its translated fact sheets for carers from CALD backgrounds.

To access Carers NSW translated fact sheets, go to 'information and resources' at www.carersnsw.asn.au

Jobs program boosts Aboriginal mental health workforce

Almost 50 Indigenous trainees have been recruited to help improve Aboriginal people's access to mental health services.

The mental health trainees have been recruited from local communities to work in areas that have a significant Aboriginal population.

"Rates of mental illness are higher among Aboriginal people, with the rate of suicide and self-harm in Aboriginal communities at least twice the national average.

"The trainees have a cultural understanding and knowledge of local communities that will encourage Indigenous people to seek access to mental health services," said Minister Assisting on Health (Mental Health), Barbara Perry.

"That's why it's so important that the number of trainees has been growing steadily since the Aboriginal Mental Health Workforce Training program started in 2007."

This program, now in its third year, is also designed to help build and expand the Aboriginal mental health workforce in NSW.

The Aboriginal Mental Health Workforce program trainees are permanent, full-time employees of NSW Health. Under

the program, trainees complete a Bachelor of Health Science (Mental Health) degree while also receiving on-the-job supervision and training.

The trainees are working in regional areas around the state including: Queanbeyan, Pambula, Goulburn, Young, Dubbo, Tumut, Albury, Griffith, Deniliquin, Moruya, Cowra, Bourke, Lightning Ridge, Taree, Armidale, Narrabri, Moree, Parkes, the Central Coast, Lithgow, Wollongong and Broken Hill.

Indigenous trainees have also been recruited to Sydney metropolitan positions in areas such as Maroubra, Mt Druitt, Parramatta, Bankstown, Camperdown, Blacktown, Ryde and Penrith.

A review of the Aboriginal Mental Health Worker Trainee program has found that the program has been implemented successfully in the areas of workplace preparation, recruitment, workplace training and support, and combining work and study.

For more information on the program, go to www.healthinonet.ecu.edu.au/health-resources/programs-projects?pid=139

New carer support groups

Central Coast

Open carer support group

When: Third Wednesday of each month, 10am-12pm

Where: Kincumber District and Neighbourhood Centre,
1/20 Kincumber Street, Kincumber

Contact: June Galea, 02 4363 1044

Aboriginal carer support group

When: First Monday of each month, 10am

Where: The SACS Unit, Wyong Public School,
Cutler Drive, Wyong

Contact: Katrina West, 02 4355 1511

Central West

Carers of people with Gynaecological Cancer

When: Second Thursday of each month, 10.30am

Where: Colour City Church, Little Brunswick Street,
Orange

Contact: Nancy Gordon, 02 6393 3380

Cumberland / Prospect / Northern Sydney

Cancer patients and their carers

When: Fourth Thursday of each month, 10am-11.30am

Where: Cancer Council Hub, Level 2, Library and
Community Building, Rouse Hill

Contact: Katherine Watson, 02 9354 2071

Far North Coast

Carers of people with Prostate Cancer

When: First Wednesday of each month, 7pm-9pm

Where: Lismore Workers Club, Keen Street, Lismore

Contact: Warren Rose, 02 6684 2201

Carers of people with Cancer support group

When: Fourth Wednesday of each month,
2.30pm-4.30pm

Where: Kyogle Memorial Institute, Stratheden Street,
Kyogle

Contact: Corinne Martin, 02 6627 0300

Carers of people with Prostate Cancer

When: Third Monday of each month, 10am-12pm
(no meeting in December or January)

Where: Alstonville Bowling Club, Deegan Street,
Alstonville

Contact: Pat Coglean, 02 6622 1545

Illawarra

Open carer support group

When: Last Tuesday of each month, 10am-12pm

Where: Albion Park HACC Centre, Showground,
Tongarra Street, Albion Park

Contact: Prue Searle, 02 4257 9036

Carers and former carers of people with Stroke

When: Third Friday of each month, 10am

Where: Catholic Church Hall, Green Street, Ulladulla

Contact: Colin Cameron, 02 4454 0371

Carers of people with Brain Tumours

When: Second Tuesday of each month, 10am-12pm

Where: "Headway", 4 Mercury Street, Wollongong

Contact: Vhari Dickson, 02 4222 5200

Carers of people with Prostate Cancer

When: Second Thursday of each month, 7pm

Where: St Marks Church Hall, Princes Highway,
Wollongong West

Contact: Dennis Hamilton, 02 4284 1942

Carers of people with Gynaecological Cancer

When: First Wednesday of each month, 2pm-4pm

Where: Banksia Room, Ribbonwood Centre,
Princes Highway, Dapto

Contact: Geraldine Beaven, 0413 383 759

Carers of people with Bowel Cancer

When: Fourth Thursday of each month,
9.30am-11.30am

Where: Acacia Room Ribbonwood Centre,
Princes Highway, Dapto

Contact: Geraldine Beaven, 0413 383 759

Mid North Coast

Carers of people with Autism / Aspergers

When: Fourth Thursday each month, 1pm-3pm

Where: Uniting Church, Albert Street, Taree

Contact: Lee Murray, 02 6650 0150

Northern Sydney

Carers of people with Schizophrenia

When: First Thursday of each month, 7.30pm

Where: Uniting Church, Shirley Street, Crows Nest

Contact: Phillipa Boss (Schizophrenia Fellowship of
NSW), 02 9879 2600

Carers of people with Mental Illness

When: Fourth Tuesday of each month, 7pm

Where: Avalon Recreation Centre, 59A Barrenjoey Road, Avalon

Contact: Michelle Rickenbach, 02 9888 1819

Carers of people with Mental Illness

When: First Wednesday of each month, 1pm

Where: Cromer Community Centre, 150 Fisher Road North, Cromer

Contact: 02 9931 7750

Carers of people with Mental Illness

When: Second Tuesday of each month, 7.30pm

Where: Dee Why Senior Citizens Centre, 34 Howard Avenue, Dee Why

Contact: Pat Boydell, 02 9453 1676

Carers of people with Depression

When: First Sunday of each month, 2pm

Where: Hornsby RSL Club, 4 High Street, Hornsby

Contact: Sandra Sweetman, 1300 794 791

Carers of people with Mental Illness

When: Fourth Wednesday of each month, 6.30pm

Where: Cottage in the Park, Corner Illoura and Stuart Streets, Wahroonga

Contact: Kate Debus, 02 9888 1819

Carers of people with Mental Illness

When: Bi-monthly, second Tuesday of the month, 7.30pm

Where: Corner Illoura and Stuart Streets, Wahroonga

Contact: Nick Baines, 02 9980 2500

Carers of people with Bi-polar Disorder

When: First Sunday of each month, 2pm

Where: Ryde Eastwood Leagues Club, 117 Ryedale Road, Eastwood

Contact: Susana Bluwol, 1300 794 991

Carers of people with Mental Illness

When: First Wednesday of each month, 10am

Where: Possum Pantry, Macquarie Hospital, First Avenue, Macquarie

Contact: Suzanne Wood, 02 9888 1819

South East Sydney

Male carers at work

When: Fourth Tuesday of each month, 7.30pm-9.30pm

Where: Various roving locations

Contact: Louise Gourley, 02 9302 3600 (call prior to meeting for location)

Carers of children with special needs (creative group)

When: Every Tuesday, 4.15pm-6.15pm

Where: Holdsworth Community Centre, 64 Holdsworth Street, Woollahra

Contact: Louise Gourley, 02 9302 3600 (respite for children on site)

Carers of adults with special needs aged over 18 years

When: Fortnightly, second and fourth Tuesday of the month, 4.15pm-6.15pm

Where: Holdsworth Community Centre, 64 Holdsworth Street, Woollahra

Contact: Louise Gourley, 02 9302 3600

Carer support groups allow carers to meet on a regular basis to discuss their caring situation, socialise, share information and offer each other support. The groups are free, although sometimes contributions may be sought for refreshments. You can telephone Carers NSW on **1800 242 636** (freecall - mobiles charged at mobile rates) for details of your local carer support group or to request a printed listing of support groups in your region. Alternatively, go to www.carersnsw.asn and click on 'Information & resources' and 'Carer support groups' to access a list of NSW carer support groups.

Thank you!

Thank you to the following individuals and groups who showed their support for carers by donating to Carers NSW over the past two months. We sincerely appreciate your donation.

B Offley	N A Kringas
D Owens	G M Armstead
Perpetual for Hamilton Foundation	A Carless
M Van Lierop	R Delfino
C Yuile	S Bowles
M L Mockler	J Murphy
Macedonian Welfare Association	J Rodieghiero
Kids and Carers Support Group Kandos / Rylstone	C Abbott
	S Herrera
	J Thornthwaite

HOME Hospice Annual Conference – Intimacy and connection near end of life

This event will discuss topics relating to end of life and encourage conversations about community, spirituality and the significance of dying at home.

This Conference is targeted at carers and service providers and will include many Palliative Care Medicine experts including Dr Sinead Donnelly, a consultant in Palliative Care Medicine working in the MidWest of Ireland since 2000, who currently works in New Zealand. Dr Donnelly has produced three documentaries on the theme of 'caring for people', which have been shown on national television in Ireland.

The Conference will take place at Sydney Mechanics' School of Arts, 280 Pitt Street, Sydney on Friday 27 and Saturday 28 November.

Registrations are available for one or both days. To get early bird rates (\$150 for full conference), register before 16 October. To register, call **1800 132 229**.

NDS NSW launches new Disability Safe website

NDS has launched a new website for its Disability Safe project, an initiative funded by the NSW Department of Ageing, Disability and Home Care (DADHC). Developed specifically for the disability services sector, www.disabilitysafe.org.au provides valuable information on occupational health and safety, workers compensation and injury management, as well as training and development opportunities. The issue of protecting and maintaining the health, wellbeing and safety of workers and service users in the disability sector continues to be of critical importance.

Specific features of the new website that may alleviate some of the pressure on organisations include:

- sample policies and procedures
- results statewide quarterly benchmarking which quantifies by organisation and by service type the number and types of workplace injuries providing a valuable self assessment measure
- online discussion forums to raise specific issues and request customised support.

Designed as an evolving and growing resource, NDS invites organisations to provide relevant content for the website to facilitate the sharing of best practice within the sector.

For further information regarding the Disability Safe project and website or to make suggestions for content, please contact Sue Smith, Disability Safe Project Manager on **02 9256 3121** or susan.smith@nds.org.au

Centrelink's 'Talking' website to make access to information easier

Centrelink will be the first Australian Government agency to introduce a "talking website". The ReadSpeaker™ technology will allow the Centrelink customers to listen to information on the agency's website.

"The new text-to-speech technology will allow customers with low vision, lower levels of literacy or those for whom English is a second language, to access Centrelink information," The Minister for Human Services, Chris Bowen said.

To see - and hear - the new feature in action visit www.centrelink.gov.au and select the 'Listen' feature.

Free Broadband for Seniors kiosks

People aged 50 and over now have the opportunity to be better connected to family, friends and the technological age with free computer training and internet access.

Under the Australian Government's *Broadband for Seniors* initiative, \$15 million is being invested over three years to install up to 2000 internet kiosks across the country.

Forty-two kiosks are already operating, with many in regional and rural areas. Current NSW kiosks are:

- Dougherty Community Centre, Chatswood, NSW
- Polish Association & Seniors Cabramatta, Canley Vale, NSW
- Cynthia Street Neighbourhood Centre, Bateau Bay, NSW
- Cooinda Aged Care, Coonabarabran, NSW
- Tingha Regeneration Inc, Tingha, NSW
- Mungindi CTC, Mungindi, NSW
- CTC Bulahdelah, Bulahdelah, NSW
- Catholic Care of the Aged, Port Macquarie, NSW
- North Coast Computer Project, Macksville, NSW
- Bowraville Technology Centre, Bowraville NSW
- Boambee Gardens Estate, Sawtell, NSW
- Sawtell Catholic Care of the Aged, Toormina, NSW
- Lismore Neighbourhood Centre, Lismore, NSW
- CPSA Dapto Seniors Club, Dapto, NSW
- CTC Sussex Inlet, Sussex Inlet, NSW
- Eden Community Access Centre, Eden, NSW
- Delegate Progress Association, Delegate, NSW
- Intereach Albury, Albury, NSW
- Intereach Buronga, Buronga, NSW
- Nepean Community College, Penrith, NSW
- Narromine Community Services Centre, Narromine, NSW
- Blackheath Area Neighbourhood Centre, Blackheath, NSW
- Springwood Neighbourhood Centre, Springwood, NSW

For more information go to www.necseniors.net.au

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DONATIONS \$2 AND OVER ARE TAX DEDUCTIBLE

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ABN 45 461 578 851

Help us support even more carers in NSW

Carers NSW is the voice of all carers in NSW. Our vision is for family members and friends who provide care across the state to enjoy improved health, wellbeing and recognition by governments and communities.

To help us make this vision a reality for the 750,000 carers in NSW, you may like to consider making a financial or in-kind donation to Carers NSW. Some of the ways in which you could help are through a bequest to Carers NSW in your will, making a donation using the form below, or by simply donating your time by volunteering with us. Whichever way you choose to be involved, you can be sure that your valuable contribution will help us to reach out to and support even more carers.

For a confidential discussion about making a bequest or donation to Carers NSW, please telephone our CEO, Elena Katrakis on **9280 4744**. Donations can also be made using the form below, and are tax deductible for amounts over \$2. All donors will be suitably acknowledged according to their wishes.

For more information about volunteering with Carers NSW please contact our volunteer coordinator, Arlene Tracey, on **9280 4744**.

Thank you for helping us to support even more carers in NSW.

New member application/donation form

Name (Mr/Mrs/Miss/Ms): _____

Organisation: _____

Address: _____

Postcode: _____ Date of birth: _____

Phone: _____ Email: _____

I am a primary unpaid carer YES/NO

I would like to join Carers NSW YES/NO

I would like to make a donation of \$ _____

Total amount payable \$ _____

I am happy to have my donation recognised in *Carers News* and the Annual Report (name only) YES/NO

Please find enclosed:

Cheque/money order or Charge my credit card Amount payable _____

Credit card details:

Visa MasterCard

Card name: _____

Acc. No. _____ / _____ / _____ Exp Date ____ / ____

Signature _____ Date ____ / ____ / ____

Please return to Carers NSW, PO Box 20156, World Square NSW 2002 or fax to 9280 4755

Privacy Statement: The right to confidentiality and privacy of members of Carers NSW is recognised, respected and protected by Carers NSW in accordance with the Privacy Amendment (Privacy Sector) Act 2000.

Membership:	
carer/individual:	FREE
carer support group:	FREE
non-profit organisation:	1 year \$66
corporate/government:	1 year \$165

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