

Print media story - Camden Haven Courier

A face and voice for carers

FULL time carer and mum, part-time journalist and marketing guru, Jan Dennis was recognised in the NSW Parliament last week for her part in creating a beautiful book about carers in the Hastings.

Member for Port Macquarie, Leslie Williams used a speech in Parliament to recognise the dedication of local carers from the community.

During a debate about the launch of the NSW Carers Strategy, Mrs Williams told Parliament about the work of the Port Macquarie Carers Group and the launch of the second edition of their Carer Profile Project.

"In early April the Minister for Ageing, John Ajaka visited the Port Macquarie electorate and his genuine compassion and honesty meant he spent a considerable amount of time during that day talking to local carers," Mrs Williams said.

"The Minister joined with me to meet the Port Macquarie Carers Group, convened by Dawn Davies who is employed by a local disability service provider, ACES, and who is herself a carer. She and I shared a belief that the Minister should hear firsthand from carers who were facing challenges in their everyday lives.

"The carers group originated in response to the realisation that carers in our region were isolated, disempowered and had poor quality of life and health expectations. The group started in 2006 and monthly meetings are held at the Port Macquarie Neighbourhood Centre.

"One of the recent highlights and real milestones of the group was the launch of the Carer Profile Project which I launched during Carers Week last year," Mrs Williams said.

"The idea for the project originated from local carer Jan Dennis who could see the benefits of compiling a collection of carer profiles that were honest, concise and heartfelt. She believed the project could be used to raise awareness about the challenges carers face."

Mrs Williams launched the book and acknowledged the dedication and commitment of carers.

"They play an important role not only in the lives of individuals but also throughout the community. Erica Lake coordinated the project, supported by Dawn and Jan," Mrs Williams said.

The book is available for purchase from the ACES office in Acacia Avenue. The cost is \$10. It is also available to borrow from Port Macquarie, Laurieton and Wauchope Libraries.

Jan Dennis said the recognition in parliament and launch of the book will bring attention to the needs of carers.

"Having Leslie Williams mention the book project in Parliament gives us hope that our objective of being able to put real carer stories in front of key decision-makers is finally coming true," Mrs Dennis said.

"She has promised to pass on the book to NSW Minister for Ageing & Disability John Ajaka and others on our behalf. Although we had that meeting with him in April, I'd like to think that was just the start of an ongoing dialogue between us.

"I have applied for a session on the carer book project to be included on the agenda for the Australian National Carers Conference in the Gold Coast in November. We'd like to challenge carers groups around Australia to put together a similar book of stories so that every NSW Parliamentarian is



Honest, heartfelt: Jan Dennis wants to see other communities bring the stories of local carers to the table of our nation's leaders.

presented with a book outlining the challenges the carers in their electorate faces and every local library has a copy. It's all about raising awareness and garnering more support."

Emerging themes and issues

Although every carer and their situation is different and unique, a number of common themes have emerged. In a poignant conclusion to each of the carer profiles, the participants were invited to share their top three wishes. The key themes and critical issues raised are summarised below.

Accommodation - many carers include the words "safe" or "appropriate accommodation" in their wish lists. They worry about where their loved ones will live once they are gone or are unable to care for them. Some carers have a clear picture of the type of accommodation model that would work for them and they are keen to move forward to see these concepts implemented. Our local carers have witnessed what happens in under-resourced or inappropriate group homes and they despair at the lack of availability, flexibility and choices when it comes to finding long-term accommodation.

Respite - although the situation has improved in our local area recently, carers find it extremely difficult to access respite with people or organisations they can trust. Most have horror stories of instances when basic medical, physical, psychological or dietary needs have been ignored.

Isolation - carers often find their caring duties result in them becoming relatively housebound or unable to lead a normal community life. Many carers are abandoned by their partners and/or families. Carers can also find themselves unable to engage fully in the workforce, pursue hobbies or become involved in

social activities at the same level as the rest of the population.

High stress levels - relief is needed from the constant responsibility and worry of caring. Most of the illnesses carers suffer can be traced by to the constant stress of caring.

Fear of the future - some carers, particularly those who are older, avoid planning ahead as appropriate, safe, affordable options for the long-term care of their loved ones are not available. They fear the person they care for will end up frightened, alone, vulnerable, unloved and misunderstood.

Problems locating and accessing support - many carers are confused by or not fully aware of the support services available and struggle with the complex application forms and processes. Carers often hear about support services via word-of-mouth. Many have misconceptions about what support is available and the eligibility criteria. Complex forms and bureaucratic language full of acronyms and "disability sector speak" are commonplace. Services seem to be named after the funding program, rather than the actual service supplied. Some carers report being blocked from professional services by therapists and support providers who fail to acknowledge the full picture of needs.

Co-morbidity - disability conditions are complex and ongoing and currently too little is understood about condition overlaps. Several carers have encountered frustration accessing appropriate services in instances where Down Syndrome and Autism occur together, and where intellectual disability and mental health issues occur together.

Economic challenges - many carers carry a demanding financial load providing personal care, supervision and transport for their disabled family member. A return to the workforce may not be possible. Single carers often carry a burden of high costs for medical interventions, therapies and equipment. Those who do receive disability support or Carer Allowance payments have expressed sincere gratitude for this small assistance.

Concerns regarding the NDIS - there is an increasing volume of "mistruths" and rumours about what will happen under the NDIS. Some service providers paint a disturbing picture of life once the NDIS has been rolled out in our area, which is causing a great deal of stress and confusion for carers. With a start date yet to be confirmed in the Port Macquarie area, carers feel like they are holding their breath waiting for this new system to arrive. In the meantime, urgent needs go unaddressed and unheard.

From the book:

"Leigh will need substantially more support as age continues to impact my strength and ability to care for her.

"I worry about Leigh's future accommodation, health, safety and happiness. I am concerned about my own health and diminishing ability to care for Leigh."

Peg, 83, who cares for her daughter Leigh, 49.