

Support For Carers in the Health Workforce: A Two-way Street

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Abstract

This paper discusses how a project focusing on Priority 5 (*Carers are supported to combine caring and work*) of the NSW Carers Action Plan 2007-2012, has delivered tangible benefits to working carers in the Central Coast sector of the Area Health Service workforce. Furthermore there have been substantial gains for the Health Service. Workforce carers are staff who balance the dual demands of employment and their caring responsibilities for someone who is frail aged, has a disability, mental health disorder, alcohol or drug dependency, dementia, HIV/AIDS or a chronic illness. Under the NSW Carers Action Plan government agencies are required to investigate ways to improve access to information promoting flexibility in the workplace for workforce carers and their employers. This Workforce Carer Project promotes the existence of the Web-based *Working Carers Gateway*, provides working carers with assistance to navigate services and disseminates evidence for policy development. By supporting carers in the workplace, informal partnerships have developed where our unit is in a position to consult with workforce carers on issues of immediate concern to all carers such as carer access, recognition, respect and validation as partners in healthcare. The project has resulted in gains for both the unit and workforce carers who offer their expertise as quality monitors for health service improvement providing an insight from the carer perspective. As a result of recognition and support for their caring role, workforce carers anecdotally report that they are more likely to recognise “hidden carers”, and respond sensitively to carers accessing the health service. The business case for supporting workforce carers goes beyond the immediate benefits of consultation, to the retention of a skilled workforce, a cost saving in avoiding re-training, and a workforce whose staff mirror contemporary consumer and community profiles.

An elderly patient was sleeping with his wife beside his bed. As she and I chatted I said that I thought in delivering total care, the person sitting by the bed was as important as the one in the bed.

I checked with Mrs T if she needed some help.

She tearily replied, "No, at the moment I'm OK, I have friends and family and we'll see how he is once he gets better. Thanks, though for asking and recognising the carer's needs".

The next day I was talking in general terms about this conversation to my friend who is also a carer for her terminally ill husband. She commented that she personally finds a lot of support in a kind word of recognition and being asked if she is OK? It goes to show how a few words can make the difference to a carer's day - they do not always want something DONE for them.

Voice of workforce carer RN

The Central Coast sector of Carer Support in Northern Sydney Central Coast Health (NSCCH) directly supports those staff members who balance their employment with their unpaid caring responsibilities. The initiative is known as the Workforce Carer Project. As an employer, NSW Health is one of the agencies responsible for implementing Priority #5 of the NSW Carers Action Plan (CAP)¹, along with the Office of Industrial Relations, the Premiers Department, NSW Industrial Relations Commission, and Department of Ageing Disability & Home Care (DADHC).

Strategy 5 “Carers are supported to combine caring and work” is of particular relevance to this paper. This ‘whole of government’ strategy is designed to assist all public sector agencies to apply existing policies to employees with caring responsibilities.

My opening story illustrates why we find supporting workforce carers is a two way street. A workforce-carer who is a RN in an acute care setting shared the story. Without the workforce Carer Project there would have been very little support for this employee, and conversely we would not have had insight into carer issues within this health service. **This is a two way street.**

How did we do it?

The CSU initiated the Workforce Carer Project in 2003 to explore issues for that particular population of employees.

Focus groups and a written survey gave a voice for workforce carers to raise a number of ongoing issues, and the project offered a platform to raise additional issues in the future. Some respondents wanted to network, while others did not want a support group, however several common themes across all caring domains became evident:

- The need for carers to have information and practical advice about the caring role
- The need to be acknowledged and valued in their role of carer
- The need for others to appreciate and understand the impacts of caring; emotional, physical and financial
- The need for strategies to address the “losses” associated with caring

In addition to these common themes, many workforce carers reported the challenges of balancing work and care.

Given the high percentage of females in the health workforce², and the fact that the caring role often falls to those with some medical knowledge or association, the number of staff in our health service who are carers is

¹ NSW Carers Action Plan PD2007_018 NSW Department of Health 2007

² The findings from the survey and focus groups found that women are more likely to undertake a caring role, in line with the reported national statistics – 71% of primary carers are female (Australia’s Welfare 1999 Services and Assistance, Australian Institute of Health and Welfare). Many carers give up or reduce their working hours, miss out on career or job opportunities, manage on lower incomes, and struggle to save for the future. Women are particularly disadvantaged in their ability to accumulate retirement savings (NSW CAP).

significant. "I am the eldest daughter and a nurse...it was expected that I would be the carer" is a survey response representative of many.

Others reported feelings of guilt when taking time off to attend to an ageing parent, on top of time off for children. These uneasy feelings can be coupled with emotional turmoil at work as a result of concern for the daily welfare of their parent... "going home from a position of responsibility and large workload to carer problems and more responsibilities creates enormous stress, after a period of time".

As well as the stress of juggling roles, Carers told about their isolation, feelings of being "trapped" and exhausted. Respondents identified that because they worked in Health, other health professionals expected that they would understand all that is required for the person they care for ... "I am from an acute care background and have no knowledge of discharge planning". Workforce Carers sometimes felt that their professionalism was challenged if they asked questions.

Armed with information from the survey and focus groups, the Carer Support Unit developed a plan encompassing a range of strategies to offer flexible support to a wider cross section of Workforce-Carers. Several strategies to promote the project are used:

- (i) simple one page notices emailed sector-wide titled "Who Cares for the Carer?", etc.
- (ii) flyer attached to pay advice of all Central Coast employees asking "Do you help with personal care, transport, social support, medical appointments, emotional support, decision making?"
- (iii) negotiated with Security staff to issue the flyer to all new staff with their ID tag
- (iv) CSU in-service or presentation the Workforce Carers project is always outlined as a foundational component of the team's role. Frequently there is one or more Workforce Carers either current or past in the room – we know many staff do in fact juggle both roles.
- (v) The Workforce Carer page on the Central Coast Carer Support Intranet site allows staff to browse FAQ, resources, links to relevant HR policies, and access phone numbers such as Employee Assistance Scheme, etc
- (vi) Through *ad hoc*, opportunistic involvement – (talking to Ward Clerks, cleaners, IT personnel, etc.) the team frequently encounters staff who are hidden carers, or who have not yet contacted Carer Support.

Workforce Carers who choose ongoing contact are contacted approximately every three months (if that is their choice) to invite their questions. They are frequently reminded they are welcome to discuss issues, or seek help or to explore options to assist in their caring role. Carers are assured that confidentiality is respected. Many Workforce-Carers make regular contact with the team to discuss best practice in the health service. Information on forums, seminars, changes to eligibility for services, etc., are relayed via email

or posted mail. While Carer Support does not offer direct support to carers in the community, we do support workforce carers to navigate local community services, access counseling, and take care of their own health needs. The CSU promotes workforce carer self advocacy in negotiating flexible working conditions. Workforce carers are assisted by initially being listened to, and help may be offered to unravel the issues and present a clear case.

For current accurate information for working carers CSU promotes the web based **Working Carers Gateway** (<http://www.workingcarers.org.au/>) for its excellent fact sheets, advice and guides. If a workforce carer does not have internet access then relevant copies are printed and mailed.

For working carers the site holds much advice in workplace tips and strategies for improving negotiating skills with their employer. Employers can access information to inform and assist in creating carer friendly workplaces. The Gateway promotes the concept that allowing flexibility in the workplace is mutually beneficial for employee and employer. Isaac Smith, Project Coordinator from the Working Carers Gateway has a practical workshop tomorrow at this conference where he explores the issues around disclosure of the caring role to employers and/or work colleagues.

What we have learnt from health service workforce-carers - the realities and issues they face

Workforce carers in NSCCAHS known to Central Coast CSU have shared some of their most personal stories in discussing their challenges. Some of their issues centre on the **workplace** - being unsure of leave entitlements, feeling uneasy taking time off for caring responsibilities, and concerns over disclosing personal information to managers and work colleagues. Additionally, workforce carers seek support to access services and information to assist in their **caring role**, and to access counseling services to talk over the stresses of caring relationships and balancing work/caring/life. Workforce carers reveal they put their own health needs on hold. CSU promotes “self care” and encourages employees to actively pursue their own health checks, offers strategies to manage difficult situations, to take “time out”, and to maintain a sense of well being.

- Workforce-carers can feel **uncomfortable** accessing leave to which they are entitled. We have learnt from a staff member who juggles paid work with caring for her adult child with a lifetime disability, that when she took long service leave to attend to the child’s additional health needs, the workforce carer felt *“really bad, knowing that her co-workers will be burnt out when she returns”*. We hear from workforce carers who juggle significant carer loads while maintaining a solid commitment to their paid work, often at the expense of their own health....*“Yes it is juggling - which hat am I wearing, and where am I going?”*
- Another, also caring for a child with a profound lifetime disability emailed saying *“The information re. carers leave and flexible work practices was (also) very interesting. I am hoping that the workplace will be agreeable to some flexibility next year.”* The CSU’s Workforce Carer project

- disseminates **information** about the range of leave policies and suggests staff contact HR for clarification of their personal situation.
- Caring for another may be **stressful and socially isolating** - many express the sentiment *“it is really helpful talking to someone”*. The CSU offers support by talking through issues with workforce-carers if their concerns are carer related, or refers to EAP³ and external counseling services if staff are seeking formal counseling (*“there are days when I cannot string five words together without crying in frustration”*).
 - *“Looking for respite for my mother.....I don’t know where to start”*. Workforce carers as health professionals may express **bewilderment or even embarrassment** not knowing of services to support them in their caring role. *“I know what I want but I don’t know the lingo”*.
 - *“In my service, we make the referrals....it never occurred to me I might use them myself!”* This note came from a workforce carer after successfully accessing services for his ageing parents. He had been making client referrals perhaps without a clear understanding of the role and function of the service taking the referral. Workforce carers report they feel **more confident in recognising and supporting carers** in their workplace.
 - Workforce carers may be unaware of pertinent information and learning opportunities *“Thank you so much for letting me know when these forums are on. I finally got to one and I found it quite helpful. I had been looking for a clinical psych and an OT for my son for years and I found them at the forum. I haven’t been able to attend any before due to work commitments”*
 - Workforce carers may be very conscious of their privacy and confidentiality, thus be reticent to share their situation and work/family issues with managers or work colleagues, placing them in a problematical situation in terms of personal and workplace support.

‘The Two Way Traffic Flow’

Carer Support believes that workforce carers who are recognised and validated are an invaluable asset to the health service not only as service improvement monitors but also as agents to raise carer awareness.

The business case for the health service to identify, retain and support workforce-carers is growing and strong at both the grassroots and corporate levels.

At the health service/patient interface (**grassroots**) level, the Central Coast CSU:

- Records and submits for **service quality improvement**, the patient journey stories from workforce-carers when either they or their care

³ Employee Assistance Program (EAP) is a confidential counseling service for staff. Counselors are trained and experienced to assist in dealing with both work and non-work concerns. They can help identify changes to consider making, assist in setting goals and develop a plan of action.

recipient access the health service. Workforce carers provide a highly valued insight from the carer perspective that would probably not be aired, eg *“Medical staff need to listen to carers. My father recently had a delirium and was in CCU. No one would listen to me. It took 10 days before he was finally diagnosed with a delirium. I am a nurse and I still wasn’t listened to”*.

- **Consults** with workforce-carers recognising them as highly valuable experts for service improvement and quality monitoring within the health service. Additionally, we recognise workforce-carers are a vital resource to check the accuracy of information and to discuss new initiatives. Workforce-carers with relevant interest are invited on occasions to comment on health service planning in our health system (eg Child & Family Health Survey for children with complex health care needs).
- **Acknowledges** workforce-carers have a source of information pertinent to their role both as employees and unpaid Carers. They are more likely to recognise people who are in a caring role but do not relate to the term “carer” and thus remain a hidden carer (neither the patient, the carer or the health service gain from this situation). Their intimate understanding of the issues associated with caring relationships makes them well placed to sensitively respond to carers - in fact several have commented that because they themselves are supported, they are more capable of supporting carers in the workplace. Workforce carers anecdotally tell us of instances where they share pertinent knowledge with patients and carers in the workplace – sometimes the very same resource information that they acquired from CSU. They tell us that their own experience combined with the CSU’s awareness raising equips them to recognise, respect and validate carers in the health setting. This was very much the case for the RN in my opening story.
- Seeks advice from workforce carers as an **expert source of critical feedback** for Carer Support initiatives such as the 2007 Carers Hypothetical. Workforce carers provide valuable feedback to the health service by critiquing draft patient/carer brochures
- Finds that promotion of the Workforce Carer Project provides an opportunity to **raise carer awareness** for all staff, and to remind them of the role of carer support in the health service. On occasions ‘doors have been opened’ when a relationship has been forged with a workforce carer, it becomes easier for the team to introduce a carer focused initiative in the ward or department.

Carers bring skills, knowledge and experience that can benefit the health service. Carers Australia in their Submission to the Job Seeker Classification Instrument Review consider carers “are an integral part of the health system and are the foundation of our aged, disability and community care”.

At the health service **corporate** level, the Workforce Carer Project guided by Priority #5 of the NSW CAP, promotes flexibility in the workplace for workforce carers and strives to improve access to information for both workforce carers and their employer.

Several government instrumentalities, parliamentary inquiries, and research institutions consider the impact of an ageing society and ageing workforce, and present a strong case for employing and supporting workers who provide informal care for family members.⁴

Governments and research institutions in recognising this emerging issue and its workforce implications are heralding the need for changes in the workplace, specifically flexibility.

It is well recognised that **flexible working opportunities** benefit everyone: employers, employees and their families. Flexible working opportunities make good business sense and enable an employer to:

- retain skilled staff and reduce recruitment costs;
- raise staff satisfaction and morale and
- decrease absenteeism

There are additional less apparent losses with the resignation of staff who can no longer juggle work and care. These can range from the cost of loss of corporate knowledge, lost time spent by managers in selecting, inducting and training new staff, to costs of the lag time in filling vacancies, etc. A director of a large company in the UK gives a compelling reason for supporting carers in the workplace – *“With a caring emergency you are not dealing with an absence, you are potentially dealing with a vacancy if you don’t respond appropriately. The cost of recruiting is incomparable to the cost of 2-3 days emergency leave”*.

Where to from here?

The team has researched and prepared a position paper offering an overview of significant relevant literature, and government and academic initiatives.

The paper is intended for workforce senior management and will:

- describe the nature of some caring responsibilities
- highlight trends and emerging issues
- examine State and Commonwealth responsibilities to the workforce
- outline NSCCAHS’s responsibilities to support workforce-carers
- argue the business case in supporting workforce carers
- present selected current initiatives

⁴ For example:

NSW Office of Industrial Relations; and SageCentre <http://www.sagecentre.nsw.gov.au/work-and-retirement/career-and-work/caring-and-work>

Australian Parliamentary *Inquiry into Better Support for Carers*

Taskforce on Care Costs 2007 Report *The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability*

- examine a hierarchy of Plans to identify support for workforce-carers

With a need for improvement in management's understanding and appreciation for flexibility in the workplace for workforce carers, Carer Support intends to share our experiences with Human Resources and Workforce Development to continue to developing NSCCHS as an employer who welcomes and supports employees who juggle work and care.

A relationship has been made with the Employee Assistance Program that has resulted in reciprocal referrals, and a modest change relating to recognising the Carer role in their presentation at new employee orientation....small steps, but ones that have the potential to grow.

A new round of promotion is underway with a wallet-sized trifold notice displayed in a clear pocket attached to an A4 poster promoting the Working Carers Gateway. The notices give a concise definition of who is carer, and who is a workforce carer, CSU's commitment to the NSW CAP and key contact details. They serve to inform all staff, and will be displayed in staff lunchrooms, etc.

Conclusion

The Workforce Carer Project is a highly successful initiative in the health service that supports priority #5 of the Carers Action Plan, supports staff who balance care and work, raises carer-awareness, highlights the role of carers, and supports staff in their interaction and engagement with carers.

Reflecting back to my opening story.....the RN by the bedside really illustrated several of the Priorities for action in the NSW CAP. Firstly she recognised, respected and valued the carer with the patient, she was prepared to offer support, and she saw the carer as a partner in care. The RN has related to us that the support afforded her has enriched her practice, and in return she has informed our practice throughout her long and emotional carer journey. She is now a graduate carer but continues to keep ongoing contact and share her insight.

