Carers
Australia

Submission
to the
Senate Community Affairs References Committee

Inquiry into Aged Care

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Introduction

Who we are

Carers Australia is the peak organisation representing Australia's 2.5 million carers. Our mission is to be the national voice of carers. Our vision is for an Australia which accepts its responsibilities for caring.

Our members comprise the state and territory carer associations, who provide services directly to carers in their respective states and territories. Each of these members is represented on our Board.

The evidence to support our comments is based on the experience of our member carer associations, in their direct dealings with carers and service agencies in their states, and other stakeholder organisations such as the National Alliance of Young People in Nursing Homes.

Aged care and the ageing population

Aged care is a major concern for many in our community and will become increasingly so as our population ages.

The National Centre for Social and Economic Modelling (NATSEM) has recently undertake a study for Carers Australia which highlights just how much Australia relies on people providing unpaid care to older people needing assistance with the everyday tasks of living to enable them to continue living at home.[i]

In 2001 there were 57 primary carers for every 100 people over 65 years of age with a severe or profound disability needing care and living in the community. By 2031 this ratio is projected to drop to just 35 carers for every 100 people aged over 65 needing care.

While the number of carers of older people will grow along with the general population growth by 57% from 198,000 in 2001 to 312,000 in 2031, the number of older people needing care will grow at a much greater rate. In 2001 there were 539,000 people over 65 years with a severe or profound disability. By 2031 this is projected to increase by 160% to 1,390,000 people. The biggest change will be in the number of people aged over 85 years. People over 85 years currently comprise just 1.4% of our population. By 2031 this group will be 3.5% of the population.

The population share of the 65 years and over age group will increase most sharply from about 2011 (when people born in 1946 would be turning 65) and that of the 80 years and over age group some 15 years later, from around 2026.

The projections made by NATSEM are based on well established demographic trends resulting from changing fertility and mortality rates. The assumptions in the modelling on the type of care provided relate to current ratios of formal community and residential care and assume they will remain fairly constant. The modelling also assumes the rate of severe and profound disability in older people will remain constant as there is no conclusive evidence to suggest this is changing, although substantial advances in medicine in areas such as dementia may change this.

This research and its projections beg obvious questions of how people needing care will manage, where the care needed is going to come from if primary carers (usually family members and close friends) are not available to assist and how primary carers will be supported in their caring role.

With most people preferring to live and be cared for at home, our community care system relies heavily on the unpaid, informal care of their family and friends. The Australian Institute of Health and Welfare estimate that carers currently spend 1.192 million hours per year giving unpaid care to family members and friends, which is the full time equivalent of 653,170 people. (This is compared to 195,313 paid full time equivalent positions in community services including childcare.) This unpaid care is worth $19.3 billion per year or 45 per cent of the total value of welfare services in Australia in 2000-01.

As the NATSEM research shows, there are likely to be many more people living in the community who cannot rely on the assistance of an unpaid primary carer. At the same time, Carers Australia also knows that the demands on carers are constantly growing as they are required to take on more nursing duties; waiting lists of formal home and community care services and residential accommodation grow; and people are being discharged from hospital sooner.

This research has highlighted an issue that will impact on most Australians sooner or later. As a community we need to plan for the future and think laterally about the sort of care we want and expect, where the care will come from, how we can encourage and support carers, and how the care will be paid for.

The remainder of this submission will address the Terms of Reference for the Inquiry based on the current experiences of carers and in the context of the ageing population and future demand for care.

T of R (a) *The adequacy of current proposals, including those in the 2004-05 Budget, in overcoming the aged care workforce shortages and training.*

Over recent years there have been a number of research studies to explore recruitment and retention of aged care staff, including personal care workers in community and residential settings and the nursing workforce.

In 2002 the Victorian Association of Health and Extended Care (VAHEC) and the Brotherhood of St Laurence undertook a substantial piece of research on the Home and Community Care workforce[ii]. It found a significant level of concern about the difficulties of recruitment and retention of staff, the community care workforce was ageing with 52 per cent of workers aged over 45 years; and there was great difficulty being experienced in recruiting younger people. To address this, strategies were needed to focus on the adequacy of remuneration, job structures, support and supervision processes, options for career development, and rewards and recognition for staff. This requires a coordinated effort and agreement between the Commonwealth and state governments.

The experiences of the Commonwealth Carer Respite Centres suggest the high turnover of senior nursing personnel remains problematic. Studies by the Commonwealth, Wheeler, the Australian Nursing Federation and others[iii] have each recommended strategies to increase recruitment and retention of nursing staff. These included a variety of entry and re-entry schemes, opportunities to upgrade qualifications, development of nurse practitioner roles, multi skilling for enrolled nurses, and rural and remote scholarships. Improved remuneration, training and staff to resident ratios were of primary importance, with the salary gap between nurses in aged care settings and acute health care still wide.

Current training programs for aged care staff are largely focussed on care management knowledge and skills. With family carers providing the bulk of care in the home and providing support in aged care facilities, it is important that such training include being sensitive to and inclusive of family carers. They are a key component of the aged care sector and their ongoing involvement is important to maintaining the health and wellbeing of the resident, as well as their own, and maintaining the quality of care.

Carers Australia recommends:

- **the Senate Committee consider the detailed recommendations of earlier reports and inquiries to overcome workforce shortages and that the Government work with the States and aged care service providers to address workforce issues; and**

- **that aged care training include training in the management and delivery of carer friendly practices as a core component.**

T of R (b) The performance and effectiveness of the Aged Care Standards and Accreditation Agency in assessing and monitoring care, health and safety.

Carers Victoria undertook a national consultation survey of the experiences of 119 carers in the accreditation process in July 2001[iv]

This study found that there was enormous variability in the experience of carers in the quality and standards maintenance in facilities.

- Only 12 per cent had been actively involved in an ongoing continuous quality improvement process, which included the accreditation audit.
- 30 per cent of carers had been involved in small aspects of the accreditation process, usually where the carer had been connected with the facility for more than twelve months and had a strong relationship with the staff.
- 50 per cent of carers in the survey knew little or nothing of the accreditation process or standards.

Many of the caring family members, "did not feel engaged in the operation of aged care facilities. Many carers felt marginalised and powerless. They found it difficult to raise issues of concern and be heard. They feared being labelled as difficult – as some felt they had been."

Sixty per cent of the carers in the survey did not have a good understanding of the accreditation system and felt they were not well informed about resident and carer rights in aged care homes. The jargon used around accreditation was a significant barrier.

Only five carers in the survey reported seeing the audit report for their respective facilities. These reports were all obtained through the Standards Agency by carers who were concerned and assertive.

Nevertheless, carers in the survey did value the accreditation process as crucial in safeguarding and protecting residents of aged care facilities and their families. The carers:

- Believed more spot checks were necessary. A proportion of respondents felt that quality improvements were organised for the benefit of the assessors and the quality had not been maintained in the long term.

- Considered the Agency focuses on the quality of the record keeping and paper work, rather than the quality of actual care.

- Considered that the accreditation process made no comment about the adequacy of staff to resident ratios, although these impact substantially on the quality of care.

Carers Australia recommends that the auditing and accreditation process increase , as standard procedure, the numbers of planned interviews with carers; and that facilities are encouraged to make the accreditation report readily available to residents and carers. Accreditation reports need to be consumer friendly.

T 0f R (c) *The appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.*

For many carers their greatest concern is who will care for their disabled sons and daughters when they are unable to. The physical and mental demands of caring often become too great for carers when dealing with adult sons and daughters and they must try and make alternative arrangements. Carers are reporting a chronic shortage of supported accommodation for young people (less than 65 years) across Australia. While supported accommodation is difficult to obtain, nursing home accommodation designed for aged people is often inappropriate for young people.

There are at least 6000 young people with MS, Acquired Brain Injuries or neurological conditions living in aged care nursing home facilities, of which 1100 are aged under 50 and a further 30 are under 25 years. While the physical needs of these people are being met, their rehabilitation, therapy and social needs are not. From the carer's perspective, this is frustrating, far from satisfactory and causes undue stress. For carers seeking alternative accommodation, aged care nursing home care is not a satisfactory option.

The National Advocacy Alliance for young people living in nursing homes has developed a five point plan which calls on the Commonwealth and State governments to address the issue. **Carers Australia supports this plan and recommends it to the Senate Committee Inquiry.**

In its five point plan to create choices for young people living in nursing homes, the National Advocacy Alliance calls for the following actions to be executed immediately:

- The Commonwealth Government assume a leadership role in developing an administrative framework encompassing aged care, health, disability and housing, to resolve the issues of responsibility and the shortfall in resources at both Commonwealth and State/Territory levels.

- The Commonwealth and the States/Territories agree to promote vastly improved coordination and cooperation across government sectors to ensure that young people accommodated in aged care settings have equity in access to disability services and supports and are provided with appropriate service pathways.

- The Commonwealth and the States/Territories collaborate in the development of an agreed national policy framework that commits to systemic change to resolve this issue, incorporating targets for the relocation and diversion of young people from nursing home settings where required, and ensuring the avoidance of inappropriate placement in aged care facilities in the future.

- All levels of government – Federal, State/Territory and Local – to work with the National Advocacy Alliance for Young People In Nursing Homes in the development of a sustainable service system that is responsive to the needs of young people with high and complex care needs and that allows individuals and their families to exercise their right to choice.

- The Commonwealth Parliament of Australia instigates a Parliamentary Inquiry to examine sustainable and equitable financial arrangements and a national community care service system for young people with high care and/or support needs.

  While there are particular issues about the inappropriateness of young people with disabilities being accommodated in residential aged care facilities, there is a need for increased resources to be directed towards alternative housing and support options for all people with disabilities, regardless of age.

On 28 July, the Minister for Family and Community Services announced she would be establishing an advisory body to advise her on ageing carers of sons and daughters with disabilities. Carers Australia will be represented on that body and expects that suitable alternative accommodation for such people will be on the agenda.

Carers Australia also supports the need for national research into the extent of need for diversified quality models of residential care for people with disabilities of all ages. This may require:

- Extending the capacity for the Aged Care Act to address the residential and community care needs of vulnerable people at the boundaries including special needs groups currently housed within the aged care sector, (such older people who are competent and isolated and in need of peer support, or older people with dementia who may do better in 'homelike' facilities).

- The offer of incentives for aged care providers to plan and develop specialist wings for people with low incidence disorders.

- Processes to encourage the sharing of program and policy knowledge, standards, expertise and skills in long term care between aged and disability providers.

T of R (d) The adequacy of Home and Community care programs in meeting the current and projected needs of the elderly

The Home & Community Care (HACC) Program is the main source of community care and provides services to approximately 700,000 Australians each year at a cost of $1.2 billion.

Despite annual indexation, the current demand is outstripping supply indicated by long waiting lists in some states (and some states having a policy of not keeping waiting lists) and very limited assistance being available and rationing of services to people with higher needs. *The Home and Community Care Program Minimum Data Set 2002–03 Annual Bulletin* shows that on average people receive just 38 minutes of domestic assistance a week. The 46,919 HACC clients aged over 65 years received an average of 50 minutes personal care week, while the 11,630 clients aged less than 65 years were receiving on average 2.4 hours per weeks.

While carers are a stated target of this program, only 4 per cent of HACC clients are carers and 48 per cent of care recipients reported receiving assistance from a carer. Carers are reporting to Carers Australia they are increasingly finding they are missing out on services, along with the people they support, in preference to people without carers. It appears, in an environment of resource constraints, people with no family support are being given greater priority for HACC services. Without access to support services, the stress and physical demands of being a carer is intensified. The carer carries the burden of keeping the care recipient in their home and out of residential care and without support this becomes unsustainable.

Carers Australia insists that, for caring in the home to be sustained, equal priority for HACC services for carers and those they support must be restored and maintained.

Funding for community care services needs to be increased to ensure that services are available – at appropriate levels - when needed. Carers Australia has called on the Australia Government, along with

the state governments, to make an initial 30 per cent increase to the HACC program.
This should be followed with at least 6% growth per annum (plus indexation) thereafter.

According to Aged Care and Community Services Australia, the current indexation method used for residential and community care services does not recognise the increasing costs experienced by the sector. Costs are estimated to be increasing by at least seven per cent each year while the latest indexation figure offered is two per cent. Clearly services can not continue to operate with this disparity between costs and income. Most
services have already made as many productivity gains as they can without compromising the quality of care. While this year's Budget contained increased funding for residential care, it did not have a comparable community care funding measure.

Carers Australia recommends that funding for HACC services be increased by at least 30 per cent to satisfy unmet demand for the service.

Carers Australia recommends that the funding formulae for HACC services must be changed to accurately reflect the real cost of delivering the service.

Community Care Review

In 2003 the Minister for Ageing released *"A New Strategy for Community Care – A Discussion Paper"* and established a Taskforce to make recommendations to improve the community care system and its 17 separate Commonwealth programs. This is further complicated by the vast array of programs and services in the states and their separate funding, reporting and administrative arrangements. As yet (July 2004), the Government has not responded to the findings or recommendations of this review. Carers Australia endorses the concept of a national framework linked to the broader service system. Within the community care sector, there is:

- in principle agreement with much of the shape of reform proposed in that document; *and*
- an urgent need for reform which creates a sensible and flexible program structure to meet consumer needs, reduce consumer confusion and time wasted by services on reporting on and managing multiple programs.

With the bulk of community care being provided by carers, carer recognition and support should be central to community care. Carers are not an endlessly renewable resource for the formal care system but individual people with individual needs. Any community care strategy must address the needs of carers by ensuring that the formal community care system can respond to individual care situations. Carers have a dual role in the system: they have their own needs for support and assistance to sustain their caring role and they are themselves key providers of essential services in an unpaid capacity.

It is therefore vital that the proposed strategy address the needs of all carers. The proposed framework in the discussion paper is overly focussed on aged care when it needs to encompass the entire HACC target group – most carers are of workforce age, predominantly caring for a partner with a disability.

Better service provision must be the main aim of a new community care strategy. In principle, Carers Australia strongly supports the concept of aligning programs and services with levels of need into three tiers of services provision and linking these with clearer pathways. But without increased funding, a new strategy will make little difference to the everyday lives of carers.

T 0f R (e) The effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care setting or back to the community.

In order for people to return to the community upon discharge from hospital they mostly rely on family and friends as carers for support. Too often, carers are reporting to the carer associations that "they are not meaningfully involved in discussion and decisions about discharge from hospitals, that they face enormous pressures to make a hospital bed vacant by taking home or deciding on placement for a relative assessed as requiring residential care; that information and coordination of supports following discharge are inadequate; and that their own needs are frequently ignored and seldom assessed".

The attached paper "Slowing the Revolving Door: a focus on carers in acute and primary health care" was presented by Julie Nankervis, a policy adviser at Carers Victoria, at the national conference convened by Carers Australia in 2003.

The paper provides an excellent summary of where carers fit within the health and community care systems and the problems this causes them; the barriers they face in having their role acknowledged in a meaningful way; and a range of suggestions to address the issues. **Carers Australia recommends this paper and its suggestions to the Senate Committee.**

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[i] The National Centre for Social and Economic Modelling, "Who's going to care? Informal care and an ageing population", Carers Australia 2004

[ii] Philipa Angely and Belinda Newman, "Who will care? The recruitment and retention of community care (aged and disability) workers", Victorian Association of Health and Extended Care and Brotherhood of St Laurence, November 2002

[iii] Commonwealth Department of Health and Ageing, "Recruitment and Retention of Nurses in Residential Aged Care Final Report, 2002

Wheeler L, "Resisting the Quick Fix – Workforce Planning to Deliver Services to Older Australians 2020", The Myer Foundation, 2002

Ministerial Advisory Committee on State Regulation of Nursing Homes", Report the Minister for Aged Care, Victoria, 2001

Australian Nursing Federation, "Analysis of Nurses Wages", 2003

Nursing Board of Victoria, "Review of aged care nursing component of the Undergraduate Nursing Program", 2002

[iv] Carers Victoria, Final Report for the Lessons Learned from Accreditation Working Group Carer Consultation Project, 2001

Attachment

Slowing the Revolving Door: a focus on carers

in acute and primary health care

Julie Nankervis

Presentation at

Caring Matters: a national debate

Canberra 18-19 September 2003

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Introduction

We come together at this Conference to debate Caring Matters. The question I put to you is why, as key stakeholders in the health reforms taking place in this country, are carers consistently overlooked and ignored?

From carers in contact with Carers Associations, carer services and support groups around Australia, we hear that they are not meaningfully involved in discussion and decisions about discharge from hospitals (especially large acute metropolitan hospitals); that they face enormous pressures to make a hospital bed vacant by taking home or deciding on placement for a relative assessed as requiring residential care; that information and coordination of supports following discharge are inadequate; and that their own needs are frequently ignored and seldom assessed[iv].

Longitudinal research conducted in South Australia found that *"the presence of a carer overall seemed immaterial to hospital staff at the time of preparation for discharge*." The authors concluded that "*the role of, and burden on, the carer went frequently unrecognized by members of the health system until major problems occurred that necessitated emergency action, often at high cost, such as hospital re-admission for the patient, or carer illness."*[iv]

As the key primary health care manager following discharge, and indeed in preventing hospitalization of people with chronic conditions, from a carer view point GPs seem to fare only slightly better in identifying patients who are carers or in focusing on carers in the treatment and care of other patients[iv].

Yet, family members and friends make an enormous contribution to better patient outcomes, the continuity and quality of health care, and the more efficient use of health resources. Moreover, failure to consider carer needs can result in two, not one, consumers of the health system.

> "*I just feel that hospitals expect you to be able to cope no matter how tired, worn out or distressed you are. Surely they must be able to see. Many people here told me they thought I would die first as I looked that bad."* (Marjorie, a rural carer).

Carer Contribution

The contribution carers make to the care of people with acute, chronic illness and disability in Australia equates to 74% of the total amount of care provided, far outweighing the role played by formal health and community services[iv]. Moreover, very few people needing health and social care rely solely on formal services. The ABS report on Caring in Families found that 92% received ongoing assistance from family and friends[iv].

Think of the carers you know and their contribution to health care. It will take a myriad of forms and will often be harder after hospitalisation. Caring may mean medical care such as changing colostomy bags, PEG feeding and wound management; administering or supervising medications to ensure compliance; providing or encouraging therapy regimes to improve and maintain functioning such as specific or general exercise.

It can also entail providing a supportive environment that minimizes risk factors such as assisting mobility and transfers to prevent falls, encouraging and modifying cooking and eating habits to accommodate changed dietary needs, and supervising patients with cognitive impairment.

Such assistance may involve dealing and living with the depression, frustration, anxiety or denial that accompany the illness itself or the changes in lifestyle required by the patient. The carer role in addressing the psychological or emotional components of self-care and recovery is particularly challenging for carers but largely invisible.

Health care also involves coordinating and accompanying patients to medical and allied health appointments, and being alert to changes in the person's health that may require attention from the GP, nurse, or hospital from which recently discharged.

Central to the patients ongoing health and well-being is the contribution family carers make to their personal care - providing or supervising such activities as bathing, eating, grooming and dressing - to maintain an appropriate level of hygiene, comfort and diet. Household activities such as laundry, cleaning, shopping and managing finances also support these goals.

Carers are undoubtedly part of the health care team, yet seldom recognized as such despite the $18.3 billion their care of adults equates to each year- far out-weighting the contribution of formal services[iv].

Impacts of caring

Compared to paid members of the team, carers have very stressful working conditions. They have little choice, no background education, no shifts or paid annual leave, limited information and training in care provision, no occupational safety checks or line management support, not to mention adequate remuneration! Under such conditions, health professionals would not accept care responsibility[iv].

Providing high levels of care can place great stress upon carers, especially where they have other life commitments or are themselves aging.[iv] Caring can affect the carer's relationships with and care of other family members, and lead to social isolation as friendships and interests become curtailed. Some are forced to leave or cut back on work or studies, and many experience financial hardship, associated with reduced income and greater expenses.[iv]

Caring tasks and ongoing stress can significantly harm carers' health[iv] including injuries, exacerbation of existing health problems, lowered immunity, and poor mental health (anxiety, depression, grief and stress). A growing body of evidence[iv] indicates that such stress can irreversibly place at risk the carers own health (e.g. cardiovascular disease). Without intervention, this in turn increases carers use of health services and makes less sustainable continued care of the patient in the community.

Is it then that health care providers are unaware of the enormous role that carers play in supporting patients at home? Are they equally oblivious to the impact that caring has on family members health, so that they take for granted this free care resource and fail to meaningfully include carers in ongoing care considerations and policies?

Invisibility in health reforms

I am aware that there are many sensitive health care providers and government officers who promote a focus on carers in health policy and practice, and that some health areas (such as dementia, palliative care, and the treatment of children) have a greater articulated focus on carers. But overall, these beacons are too few and have too limited an impact in the larger scheme of Australia wide health reform.

Policies and related initiatives targeting acute and primary health care by Commonwealth and State governments reveal an emphasis on managing the increasing demand on health resources due to the increasing prevalence of illness, diseases and co-morbidity associated with an aging population. They include strategies to enhance access to elective surgery; to facilitate admission from emergency departments; to improve discharge planning; to reduce hospital stays of patients awaiting residential care; and to divert presentations to emergency departments.

Following an initial focus on internal hospital processes, the more recent emphasis has been on the interface between the hospital setting and the primary health care and community care sectors. Efficient and effective continuity of health care processes; better evidence based disease management practices throughout the continuum; and an increasing emphasis on patient self-managed care as a preventative and rehabilitative strategy are priority goals for government and health care services.

Yet, when we scan these numerous policies, funded initiatives and the processes that develop them, carers are largely invisible- a token presence at best with little weight compared to the focus and attention paid to the concerns of stakeholder in the formal care sector.

My challenges to you are these:

Why are carer issues given so little weight?
How can the barriers to a focus on carers be overcome?
What can we build on and what can we learn from the initiatives elsewhere?

Barriers to a genuine carer focus

Reflecting on our experiences in advocating to bureaucrats, professionals and service providers for a greater carer focus and participation, a number of barriers are evident.

1. Lack of visibility and empowerment

Health professionals and their institutions are identifiable, accessible and organized in voicing their expertise and needs in the health reform process. With a public duty of care, burgeoning workloads, the shadow of litigation and media exposure, health professionals and government alike have a shared interest in prioritizing and resolving the complex workforce, budgetary and patient management issues.

In contrast however, carers exist in the private realm, with few having the stamina, knowledge or time to pursue their issues or complaints through the health system or relevant professional bodies, or to lobby through their representative body (the Carers Associations or other Peaks).

While hospitalization can be a critical point in the carer journey, for most families it is episodic or short-term conract, with life quickly refocusing on the care role in the community. Few hospitals actively follow up after discharge or have in place systematic patient feedback processes that provide data on carer experiences and outcomes (such as developed by Grimmer and Moss in South Australia[iv]).

Similarly, in the broader health system there is no national framework for carer participation such as exists in mental health to guide carer involvement and feedback. Carer representatives on government and local health service committees are less accessible than consumer representatives, are thinly spread, often poorly supported and speaking into unreceptive minds.

2. Limited knowledge

Responsiveness to carers at both policy and practice levels is affected by a lack of knowledge and understanding about the caring role, the diversity of carers and how they self-identify, and the impacts care responsibility can have upon their lives.

3. Ideology

An ideology promoted by government (often shared by workers and families) that places health care in the private domain discourages greater focus. It conveys expectations that families will provide support and care at home for the patient as a matter of course regardless of their actual capacity and willingness to do so. As such, carers are assumed to be a free resource able to provide care for what has become an increasingly more dependent and complex patient population. At best they are provided with information so that they can better manage the health care role.

4. Privacy issues

The interpretation of legislative privacy requirements can militate against a stronger focus or inclusion of carers in policy and practices, unless they formally hold Power of Attorney or Guardianship authority.

5. Medical model of health

A predominantly medical model of health, with a continuing focus on clinical factors and treatments over the psychosocial components of health of which carer support is a part. For families from culturally diverse and Indigenous communities, this can have particular significance as their understanding of and caring response to illness may not fit this model.

6. Limited evidence

There is a lack of high level evidence (Levels I, II or III) about the role carers play in patient outcomes; the impact current practices have upon carer health; and the benefit of interventions including or targeting carers. In a climate of increasing emphasis on evidence based practices, level IV data based on expert opinion and anecdotal sources makes little impact compared to rigorous clinical trials, often with younger and less complex subjects than are typically supported by carers. Even when non-medical interventions are researched, seldom is a carer focus or feedback evident.

7. Attitudes

Ambivalent and sometimes negative attitudes towards families by health professions (especially within hospital settings) can prevent inclusion[iv]. Carers can be viewed as demanding, resistant and troublesome; overanxious and undermining recovery; uncaring, manipulative or abusive, or unrealistic, in denial and unable to appreciate the risks of the continued homecare of the patient.

8. Work pressures

The pressures of challenging workloads, financial and time constraints contribute to the maintenance of such attitudes, especially without positive leadership. They significantly constrain even empathetic and sensitive practitioners in the focus they can give to carer issues at a practice or service development level.

This list could go on and be fruitfully debated. But clearly there are many challenges to carers' rights and needs being acknowledged and addressed in health policies and practice. There has been much already written about practice principles and approaches to being more responsive to carers in individual patient care situations. [iv] So today, I want to focus on what may be some strategies in facilitating these practices

The way forward

Existing strategies targeting workforce attraction, distribution and retention of doctors and nurses are aimed at reducing workload pressures such as militate against a carer focus in individual practice. Similarly, strategies aimed at ensuring that only patients truly needing hospital care are admitted may enhance carer inclusion and quality discharge (although the impact on carers of people diverted to other pathways remains questionable).

What of other initiatives?

1. EPC Medicare items

The introduction in both hospital and community settings of EPC Medicare items for doctors involved in case conferencing and care planning, partly address time and remuneration barriers. The formal acknowledgment of carers as part of the multidisciplinary team, and recent guidelines regarding their participation with patient consent, provide a positive opportunity to increase the focus on carer views and needs.

Despite positive evaluation of the overall EPC initiative we are yet to hear feedback demonstrating greater carer inclusion. It is thus of considerable concern that the Commonwealth government axed money previously earmarked for the 2003-04 budget to education supporting implementation of these new guidelines. There is an outstanding need to educate GP's, hospitals, allied health providers and consumers about carers role in these items, and to develop demonstration projects in each state to explore and evaluate their benefit to patient and carer outcomes. Collaboration between health providers and Carers Associations is essential.

2. Professional Education.

There is a critical need for broader education of doctors, nurses and allied health professionals about carer issues. This focus should be introduced at an undergraduate level in universities and hospitals and reinforced throughout postgraduate and professional development education. Collaboration between Carers Associations and professional bodies such as RACGP, AMA, AGDP, ANF, and APA could be funded to identify and initiate opportunities for such education.

Preliminary work with GP bodies such as conducted by Carers South Australia and Carers NSW have shown positive outcomes but require ongoing funding and replication nationally. The recent GP-carers projects announced by NSW Health are most welcome.

More intensive and targeted education of hospital medical staff has increased awareness and changed practice in a number of overseas initiatives. For example St Vincent's Hospital Manhattan provided specific carer training to all medical students, involved them in its Carer Centre and exposed doctors to a carer perspective in geriatric ward rounds[iv]. United Hospital Trust projects at New York University Medical Centre, Mount Sinai and Brooklyn hospitals also included specific staff training strategies[iv].

3. Identification and consent procedures

Carer participation is however dependant on timely identification of carers at key points in the health system, supported by relevant guidelines, adequate recording of primarily carer details in all patient records and the availability of patient consent. Given the complexity at times encounter in obtaining patient consent to information disclosure and carer inclusion, there is a need for dialogue and best practice projects that explore proactive approaches to gaining consent[iv]. Work occurring the in the mental health sector, and in respect to Advanced Patient Directives could provide useful guidance in this respect.

4. Projects targeting carers

Existing hospital and primary health care initiatives provide opportunities to target carer issues and carer participation as a specific area for innovative pilots. Reports from projects in the UK and US demonstrate the considerable benefits derived from programs which develop best practices in carer participation and support within hospitals and local communities.

Acute health initiatives

For examples The National Alliance of Caregiving and the United Hospital Fund of New York have produced national resource guides on discharge planning for both family members and hospital staff[iv]. Other state projects funded through the United Hospital Fund[iv] include:

- The establishment of condition specific education and outreach support programs to carers from ethnic communities.
- Provision of carer resource manual, social work liaison and 12 month telephone follow-up program post discharge
- The collaborative development with carers of a dementia specific acute ward for general medical patients to optimise patient management and reduce carer stress on discharge.
- A partnership project with carers and neighboring residential care facility to enhance placement decisions and transition processes through education, carer consultation and support, and staff rotation.
- Establishment of a carer resource center within the hospital to provide carer information, education, counselling and group support, alongside advocacy, staff training and consultation, undergraduate education and performance incentives.

A similar Carer Support Centre model was developed by St Vincent's Hospital Manhattan, including ongoing outreach to carers in contact with the hospital. Alternatively, Scottish Home from Hospital initiatives[iv] involved a dedicated carer support worker being out posted to the local hospital from the regional carer service. Staff awareness raising and developing carer resources showed benefits in carer identification and referral, enhancing carer choice and confidence in care management post discharge.

Primary Health Care

Considering primarily health care, equally positive health outcomes have been reported in terms of efficiencies and health care gains by locating a carer support worker as part of the multidisciplinary primary health care team in the UK[iv]. Identifying hidden carers within the GP practices (most of whom where not liked to services) enabled exploration of the care unit's needs and preferred supports, provided tailored education, individual and group support, referral and advocacy. Other Scottish projects aimed at identification and referral of hidden carers utilized GP mail out and surgery visit strategies by the local carer centre[iv].

While our Australian context differs from both UK and US, potential to adapt such models to present directions and initiates appears considerable. Already models of collaboration have been piloted between:

- Divisions of General Practices and regional carer services[iv], with Carer Associations[iv], and with researchers[iv] to enhance carer referral and support.
- Hospitals and Carer Associations regarding staff awareness, carer education and referral[iv]

Recent adoption by NSW health of a model of carer support workers in each of its 17 Area Health Services shows leadership and commitment to systemic change beyond that of piecemeal pilots.

Needless to say, pilot and demonstration projects continue to proliferate at Commonwealth, State & Territory levels, so earmarking funding for carer inclusion or specific projects must be a priority in subsequent funding rounds. National initiatives such as the Hospital Demonstration Program, Coordinated Care Trials, Self Managed Care, and Disease Management initiates trialed through Divisions of General Practice present prime opportunities for developing carer friendly practice.

State based initiatives, such as the HARP and Hospital Demand Management Strategy projects in Victoria, significantly complement such initiatives and should be encouraged under future Australian Health Care Agreements. Other initiatives such as may flow from the 9 Reference Groups formed under AHMAC to address priority health issues should also be carer sensitive and inclusive.

5. Carer inclusive data collection

As an interim measure to the above, valuable data to guide policy development and health care practice could be gained by ensuring meaningful carer feedback in the evaluation of all current projects funded under such initiatives.

Current monitoring, accountability and quality control processes should also be extended to included a carer viewpoint on treatment and care processes, patient outcomes, attention to their own needs and health outcomes. Systematic data collection through KPI measures, service audits, QA consumer feedback surveys need review and complementing by carer consultations that provide depth and meaning to quantitative findings.

6. Research.

Substantial, comprehensive research is needed to investigate carer experiences of acute and primary health care service delivery. Compared to the population based carer study by the Harvard School of Public Health and the United Hospital Fund[iv] and sequential national surveys conducted by UK Carers[iv] in 1998 & 2001, we have no overarching research to inform health policy, program and practice development in Australia.

There is an equal requirement for quality research to identify carer contribution, needs, and effective interventions for subgroups of carers, especially those providing care to patients with complex needs or illness targeted as a health priority (such as heart and cardiovascular conditions). Submissions for research funding by academics, health services, professional bodies, or carer organizations should be given support and considered by government departments and bodies such as NHMRC and PHCRED.

Project innovation and quality research are however of little value without dissemination and awareness of their findings or outputs. Currently, relevant research is difficult and time consuming to locate. There is an evident and urgent need for a Clearing House to collect, organize, and facilitate access to research across the acute and primary health care sectors relating to informal carers and effective practices interventions. While ARCHI is a most valuable resource regarding hospital innovations, carer related information is limited and there is no similar body catering for the primary health care sector.

7. Health Services Carer Policy

In the absence of an overarching national health policy, there is a need for a Health Services Carer Policy that will integrate and provide consistency of focus to carer issues and participation across the many programs and components of the general health system. Compared with the UK legislation or the recognition and rights articulated regarding carers in the National Mental Health Policy (and its accommodating standards) the mainstream health system is sadly lacking. There is no agreed definition of carer, no visible recognition of their role or acknowledgement of its impacts on their quality of life, nor endorsed principles for working in partnership with them.

To provide leadership and equity of support for carers, government health ministers and relevant professional bodies are urged to develop a Carer Policy that will promote a positive view of carers, foster partnership between providers and carers, and encourage attention to carer health and support needs. Such policies should provide principles and a template for carer participation at individual patient care, service development and systemic change process levels.

Policy implementation cannot however be resource neutral, and must be accompanied by meaningful financial investment to achieve carer sensitive practice. While some funding could be available through existing strategies, this commitment must be viewed as a long-term investment that will be offset by savings made in better patient and carer health outcomes over time.

Conclusion

Achieving this vision clearly requires a commitment of political will on the part of Commonwealth and State governments, and collaborative relationships between government, health professionals, patients, carers and their representative bodies.

There have been many recent calls for a less fragmented and adversarial approach by governments to resolving health care issues and for developing a shared vision that will promote the health of our nation[iv]. Carers are a vital part of that healthcare picture- in patient recovery and well-being, and as consumers in their own right.

Debate about structures and the relative funding emphasis on hospitals and primary health care in the new AHCA is welcome. For many of Australia's 2.3 million carers however, integrated care and prevention translate right now into better patient access to hospital care, meaningful discharge planning and quality patient care in acute and community care that is inclusive of carer needs and views.

I challenge you to advocate or commit to making this change.