

House Standing Committee on Family, Community, Housing and Youth

Inquiry into better support for carers -2008

Introduction:

"A light at the end of the tunnel... ?"

I am presenting this submission as a former full-time carer, having looked after my cherished father at home for the past eight to ten years. He passed away early this year, at 92 years and 4 months young: my Dad was never 'old'. He may have become physically infirm but his spirit and mind were always young, even on the gray days. Gentle, caring and generous, as always, this man of intellect and creative thought - my father. His dementia was more of a slow-going kind so we had more good time to spend together than some do. Later on though, it always seems that you've forgotten things, doesn't it?

This blight called Alzheimer's became an unwelcome part of our lives over seven years ago; an offensive word, difficult to use about someone you love dearly: so many unknowns, and still the hope that 'they' have got it wrong. Happily, Dad was always, always aware of who I was, and of the familiar faces around him. He knew too that he was in his own home, where he needed to be, with his four-paws mate nestled at his feet, another nearby.

The familiar sights, sounds and smells of a lifetime were also his daily companions, and reassurance.

The worst disruptions were the repeated hospital episodes for chest infection from the dysphagia that may accompany this awful disease. *Life-changing even more.* Apart from the continuing passage of different workers' faces and voices, and ways of doing things - the unremitting variations - he felt safe and comfortable in his own surroundings.

This is a welcome opportunity, to offer ideas and our experiences in the attempt to design something better for all. The task is consuming but necessary and yet, while hopeful, I still feel apprehensive: what will come of it, how much gain and how long to wait for changes so urgently needed?

Despite knowing that none of this can now benefit my own father, I know he would be urging me on, for the better outcome was what my parents always believed in and strove for. And that certainly is what we need for our communities right now.

Role and contribution of the carer:

Ours is a dual story here, my father's and mine, as happens in the care role. Lives become inseparable, the cared for and the carer - each supports the other, grows and gains strength from that.

This personal journey has been long and arduous but rich and rewarding; I often think of it as an Everest, one I would never have thought I could take on, let alone succeed in; I would have underestimated my ability, certainly

the 'persistability', the single-minded, on-going tenacity so often needed just to keep going. 'But if-that's-what's-needed-so-be-it' has become my catch-cry at times, as for many others.

I have been part of a cohort little mentioned or written about, but becoming more common with time: the adult child caring for an elderly parent, often at high level care, and desperately trying to keep our parent at home rather than in a nursing home. And trying to keep so many other ends together at the same time. We are not necessarily in the 'sandwich generation' for we may well be single for one reason or another and without other family support to take up the slack, but also less distracted by competing demands.

This preference, at home, can be impossible for many who would wish it otherwise. If we can and do take on this challenge, either gradually or suddenly, we probably soon discover there is little practical relief, either physical, or emotional, or financial. Can we cope? Who knows? Head down, forge on, deal with it step by step. And - lots of hope.

In general the role of the carer, the implications, the load, the highs and lows - most go unrecognized and not understood. Most people do not want to think about this stage of life until they have to; it is unattractive unless it is your own to deal with. And, to many, an intrusion into the opportunity to live life to the fullest, as we're so often exhorted to do these days. They forget, of course, that 'fullest' can mean something less obvious but far more lasting.

We are not encouraged these days to believe that happiness so often lies right before us for the reaching, but usually results from great effort. Personally, I now have no doubt what happiness means for me -the multitude of small moments of pure joy in seeing my father succeed in ways once so easy that had become so difficult: striving to stand and walk again when the geriatrician had decided otherwise; seeing him return through his own front door when a nursing home had been predicted; watching him feed and shave himself after days and days in hospital of being presumed, and treated as, incapable; and, of hearing my father speak clearly and lucidly on the phone to his sister when many would have thought this improbable. Dementia has become an easy excuse for the health care system to redirect funding to other quarters.

The above successes and many more result from challenging a system that does not allow sufficient support and time for patients who need it - our elderly - and certainly does not allow for rehabilitation or other benefits when 'dementia' is shown on paper. (This was confirmed to me on ABC radio last year, by a professor of geriatrics; it is not imagination.)

Wrap up these and innumerable other moments in our recent years of at home life and caring, and you have the reasons I feel fulfilled in what I have done as a carer; and now at a very great loss, not having my father around in my life. His words of wit and wisdom, almost to the last, were essential in my day.

Through all of this I have grown immeasurably, but succeeded less than I wanted to. It has been a privilege, the carer role for 'my Dad' - and I am fortunate, too, in that he was always able to tell me how much he appreciated my efforts, always spontaneous, frequently, and in generous words and ways. Many are not so lucky, especially where dementia plays a part, if not something else, and obstructs the telling.

The Carer & Community Care (in home):

Introduction

In the following passages I am focusing comments on 'community care' as it has affected us, most of that stemming from delivery of the in-home EACH programme, or links to it. All aspects of this 'support', directly affected me as my father's carer, so I am regarding it as valid to the Terms of Reference, although the programme itself comes under another Ministry.

Again, a carer cannot be separated from what they have to deal with, positive and negative, in all ways. In my own case, there was no-one else to take over the reins or share the intensity of the work involved. Several facility respite episodes were involved which directly affected me, and quite drastically as many carers find with 'respite'. The bulk of our experience, however, was 'in-home'.

Who cares?

There are benefits and strengths within the area of community care as it exists currently: undeniable. The greater impact, however, upon my life as a carer for my late father, and for many other carers, has come from the disability of the system itself, and/or from the unwillingness or inability of people within who could and should already have made more of a difference.

We family carers do what we do - look after someone much-loved - because we believe it the right and proper thing to do; usually on a shoestring budget, maybe with some family/friend support, most likely fighting the odds. Is it then fair or decent for the 'system', fortified in so many ways, to expect us to cope with the level of frustrations and problems that we confront daily, often hourly, in trying to manage our situation?

We endure intense anxiety, frustration and illness - witness the Deakin University report on carers' health late last year. This dreadful situation could so readily be corrected with improved processes in place. It is even possible that we might then approach something like a 'normal' lifestyle, which most of the community take for granted.

How can we even participate ?

The Terms of Reference refer to 'barriers to social and economic participation, focusing on finding and/or retaining employment.'

How best to put this? 'Participation' - in almost any aspect of life other than the caring role itself - is impossible for a full-time carer, and probably unlikely for most others; certainly not without solid support by other family or friends, IF there, AND willing and able. For me, no practical support from the personal side, several close friends in spirit and for cups of tea, but they have their own families. Most of us find support bases very thin on the ground. We shrink into our own little corner of the world and -just-keep-slogging-on.

It is frequently daunting, and disappointing, to realize the lack of understanding by decision-makers, people supposedly 'in the know', of how a carer really does fill in a typical day. Some role-playing would not go astray - our needs (not wants) might then receive urgent attention: a few days or a

week in our shoes would point up how tough the role is. But who on earth would take up that challenge - probably only a reality TV show? If any of this sounds less than subtle, however, please understand that exhaustion does that to us!

What is possible?

Most carers would hardly want to live on handouts - it doesn't pay the bills, nor raise self-esteem. But what we need in order to re/gain a foothold in the working world, is like a bridge too far.

What is urgently needed is a restructuring of the carer support processes in tandem with similar reviews within elder and disability care. As stated elsewhere, they are intimately connected.

It is to be hoped, therefore, that the focus on 'employment' here is for the right reasons, that is, directed at enabling and empowering those of us who are CAPABLE to do so. Surprisingly to some people, carers DO work already, and extremely hard; that is our job! But to do paid work we firstly we need the energy (usually in short supply), coupled with first-class support (a rare thing as yet), which might then give us some time - if we are even to think about the possibility of employment.

There are numerous aspects to this, and possibilities. Despite the inability of many carers to engage in employment, there are many of us who ^{would} find it possible and desirable, perhaps part-time carers, but particularly post-carers. We are well-placed to utilize the skills and knowledge developed over years in a care role. Several points emerge:

- domestic skills and depth of experience are very lacking in the majority of in-home workers
- Certificate 3 does not attend to this
- many of us as carers have the knowledge, experience, and level of standards to do this sort of training, in a wide range of skills
- many of us would welcome this sort of opportunity
- it could be done on a casual, part-time, possibly full-time basis

I considered this, even prior to full-time caring ~~took role~~ but my situation at the time prevented it. This sort of choice, however, would appeal to many and certainly be of benefit in various ways: financial, confidence, social contact, etc. The idea appeals, even as I write this! Again, consultation with those of us in the 'hot seat' should be an essential.

We need too, community culture change - back to the future perhaps - whereby more families resume the ~~of~~ caring for family members. In this world of self-seeking that seems rather unlikely THIS week. But - incentives perhaps? Meantime, small teams of properly trained, really competent people with kind hearts who are paid well enough to get it right, as we need it done in our own homes. We might then be able to leave home for a while without being worried sick as to whether, and what standard of care is being meted out to someone we love in our brief absence (if we're lucky to be out in the first place). But please don't suggest the facility option - that is why we care 'at home'.

The grinding, blinding obstacles

The obstacles, hurdles and hoops that I personally have had to negotiate, and others I know, limited my time, energies, finances, and more importantly, my time to be a daughter to my father when he needed me most. To the reader they may seem minor in some cases, but when part of a carer's hours and days, they become intense.

Importantly:-

Issues affecting carers -their needs and difficulties- must be considered alongside the care recipient's disability or ageing status, not separately from. Our lives are intertwined, a whole; we are not 'separate lives'. Each affects the other, and it is illogical to regard it otherwise.

In considering, for example, barriers to participation, or strategies for improving choices, and so on, it is essential that these are not conveniently teased away from the particulars, eg. the inadequacies of respite; a more respectful and caring culture for elders within hospitals; proper training and skilling of in-home workers; the unconscionable behaviour of many 'providers' (usually non-profits) and labour-hire agencies; the still-frightfully inadequate Complaint Scheme; the dearth of competent advocates. This but a small sample of the issues that inhibit us constantly.

A few specifics:

It is futile and wasteful to introduce new measures, strategies, processes, into any system unless the causal problems are attended to. To help improve many carer's lives, drastic and urgent action is needed in:

Community support packages:

These are currently allocated to the person cared for, not the carer. Because our lives are closely inter-connected, logic indicates that needs-based funding and allocation of some services (eg. respite or certain supplies) ought to be in a wholistic, co-ordinated way, carer and care recipient, not independently of each other as now.

eg. if a care recipient is at high level, then that carer is more likely to need extra and more flexible options for respite. At times, the need may be greater than at others. And, the needs are not the same for all recipients on EACH (or other packages); needs obviously differ for people and with time; elder needs fluctuate probably more than other people's.

The respite situation is so complex though, with so many 'buckets' of funding through so many brokers; I am generalizing to some degree. Currently, there seems no differentiation between degrees of need for carer respite.

So - as residential assessment and funding is graded, so then why not in-home packages and carer respite?

Based on a new set of principles, these packages would become far more effective and equitable, and no doubt cost-effective, than the current system whereby too many fences segregate care recipient needs and carer needs.

Various adjustments are needed, some of which could be:

- *gradations in payments;
 - *assessment levels and respite options (gradations again);
 - *flexibility between grades as need dictates, and not uni-directional;
- Again, flexibility and rewards (for Management) exist within the residential sector, so why not for those of us who choose the in-home option? This flexibility would benefit carers greatly, I feel.

Improvement in information flow and transfer is another essential. (Yet more opportunity for employment here, using carers' experience where it counts.) Often it is 'happenstance' for a carer to learn what is available and how to access it, The rules are well known by those on the governing side, little or none by us, the recipients. It is virtually hidden in many instances.

Every carer has a right to know what is available.

(Note: I am still awaiting response from Carelink after three messages left about a year ago; hardly an effective resource. And similar comments from

others. And I was effectively ignored in a Carer Respite Centre last December, I think for daring to visit not phone!)

Still more urgent attention:

1. The severe impact of the host of problems we encounter daily/weekly in utilizing the funding we receive is debilitating physically, mentally, emotionally, and only known by those of us who go through it. Words cannot relay the experience.

Some of the worst pressures occur in the following areas (some remarks here may be repeated in other sections):

a/Provider 'overlording': practice too often fails to match, even relate to the theory of the EACH regulations; an almost total lack of transparency thus lack of accountability in their modus operandi; eg. contracting between providers and 'commercials' for various services & equipment (hire or purchase), never mind the suitability, or indeed the timely paying of accounts, which then jeopardises services to the care recipient and by connection, the carer. ***** ATTACHS.

b/Agency (labour-hire) attitudes: too often arrogant and collusive - ie. say one thing and mean/do another eg. in-home workers who are supposedly appropriate, trained and capable then arrive and are not willing, don't listen, unsuited, but who are also often run into the ground by their employers and treated poorly; (more of the 'near-enough' here, so long as the dollars come in);

In co-operation with providers, they can and do so easily lie, cover up, pretend, in order to set the scene as they want; certainly a lack of transparency and certainly no accountability except on paper; ***** ATTACHS.

c/Hospital culture towards the elderly (indifference and cost-cutting) eg. lower standards in many ways for the dependant and/or chronically ill, where again 'near enough is often good enough', more in wards than casualty; of course, elders are unlikely to defend themselves in this situation, even less than normally; this frightful lack of respect for our elders is all too evident and we in Australia should be ashamed of it;

And, if privately insured, will they even take you in? We have no real way of knowing; therefore, private insurance is often wasted; ***** ATTACHS.

d/Government under-funding (at various levels) - the anomalies of the Federal/State funding system ie. we then suffer full cost-recovery for essential services and equipment if on Federal support money, eg. Royal District Nursing, HACC support services (home maintenance, etc.) ***** ATTACHS.

Can you imagine the overload for a carer, having to play secretary/ researcher/telephonist, etc., not to mention the pangs of injustice - even if they have the language and confidence - to negotiate the system?

Often the 'provider' wishes to hide information rather than disclose, in the process of steering business towards their own 'preferred providers', and/or making their own task easier, or more cost-effective (for them), and regardless of the effects upon the carer. Suitability of services or equipment is not necessarily a priority as regulated to be, and commercial contracting is often the name of the game here. Heaven help you if you challenge it! ***** ATTACHS.

2) Partnership approach - if this were adopted as a principle - regular consultation with us, the in-home carers - many needed improvements could be effected.

It is we who see the inefficiencies, the inadequacies, we know where and how dollars can be better spent to avoid the wastage that prevails.

We are accustomed to finding and employing creative approaches in our daily lives: we have to or we would not last the distance.

3/ Offering in-home care for our elders is essential, and becoming more desirable - who wants to be locked in and fade away in a nursing home? Unfortunately, the reality we currently have, as opposed to 'on paper', (both in-home and in-facility), is pretentious, wasteful (therefore less effective), and servicing the needs more of others than of us, the care recipients and carers; mountains of words on paper that act as a foil for what is really going on - ask a few carers for their inside stories!

Now, Providers know, and we know, and the Department knows, that there is no real transparency thus no accountability in the set-up of these packages; the theory in no way matches the practice; it is well known, sadly, that only good luck governs whether you end up with a terrific Provider, or otherwise. And many are intent it should stay that way. Why should 'good luck' control whether you or I receive the care and concern we are entitled to? It has to change, if true care is to be given - and ^{so} our minds can rest easy.

4/ Another imperative is that the Primary Carer' must become just that: 'primary'; again, in practice, not just theory. We are too often disregarded and subordinated by many in the 'care' field - case managers, social workers, allied services, etc. especially by case managers; if we query or challenge the status quo, we are then seen as a threat; but most carers are too tired, too afraid, or even unaware, to pursue a complaint within the system so they don't complain; they are afraid of losing whatever benefits they receive, especially if they lack language skills to speak up at all.

Most operators within the system at any level well know that the home carer and care recipient are vulnerable, very susceptible to intimidation or threats, so it is a mechanism often used to subdue us, if it works. This must change.

ATTACHS *****