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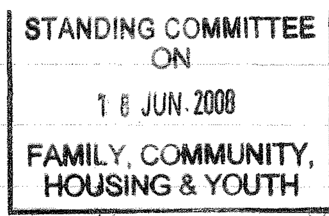
STANDING COMMITTEE
ON
18 JUN 2008
FAMILY, COMMUNITY, HOUSING & YOUTH

Submission No. 214
(Inq into better support for carers)
A.O.C. 27/6/08

Secretary
Inquiry into Better Support for Carers
Standing Comittee on Family, Community, Housing and Youth
P.O. Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600

Dear Secretary,
I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

My role as a carer is to nurse and manage at home a sick elderly husband aged 86 years who is incontinent and has very limited mobility.
My comments and suggestions are made from observations of help provided for me through an EACH package and my own experience working with Health Care Service provision.

Problems for carers.
Tiredness / exhaustion / 'burn out' / diminished quality of life / bleak future re employment / limited possibilities in financial planning for own retirement / worry re own ill health.

Action Required - Summary

a) Improve quality of practical physical help available and reorganise link between Community Nursing Sector & Community Care Programs to combine the two.
b) Improve availability of information & access system for aids - wheelchairs, hoists etc.
c) Improve level of financial assistance, increase but also reallocate funds.
d) Improve information availability re sources of help.
e) Improve transport availability & support costs.
f) Clarify help availability should a natural disaster occur - flood, earthquake etc.
g) Appoint a social link organiser.
h) Government should allocate a larger vote to Ministry/Ministries coping with "Ageing in Place" and consolidate at Federal Government level.

a) Improve quality of practical physical help available & reorganise link between Community Nursing Sector & Community Care Programs to combine the two

- Combine nursing & community health programs under nursing umbrella.
- IHC workers with certificate III in aged care should be linked with other grades in teams. 1 x RN, 1 x EN, 4 x IHC workers, 2 x support workers. This would provide 'back up' for IHC workers, training opportunities, advanced knowledge & expertise available where it is needed applied directly for patient's benefit & help to reduce administrative work between categories of care workers i.e. referrals.
- Review syllabus Certificate III in Aged Care, Level should not be viewed as an end in itself.
- Plan modules for continuing training for all certificates (Health) including those for support workers.
- Accept modules nationally & give credits towards EN training.
- Attach incremental payments in salary structure for completed modules.
- Direct Service Organisations to carry out their training obligations - allow leave for attendance some time paid, some unpaid.
- Accreditation scheme for Care Service Provider Organisations should include actual visits to clients in their homes by an Inspector to check standards of care being received; not just evaluate certificates of workers as a "paper exercise".

- Non government organisations should pay workers to standard government rates so workers in nursing homes or community with similar qualifications all receive same rates of pay.
- Employees with Certificate III in Aged Care should be obliged to follow initial training with a minimum of 6 months full time work in a nursing home before being allowed to work in the community.
- A career structure for IHC workers could thus be made giving motivation for them to stay in the same field & with further training enhance their status & improve or increase their salaries.
- Care Service Providers should be directed to employ a training officer, 1 person for every 25 employees, essential to check standards & provide on going training so services could be upgraded.
- If in-country expertise is not available nurses should be recruited from overseas on temporary visas until local employees could be phased in to meet service needs. Service being offered for those with high care dependency needs requires a skill level not being met in many instances.

b) Improve availability of information & access systems for aids - wheelchairs, hoists etc.
- A special department / central store should be set up in each regional area to store, maintain, supply & loan equipment / aids; a reasonable stock of equipment being kept on site.
- There should be an exhibition area where a number of commonly used aids could be displayed which is open to the general public so visitors could view & discuss use of items. Display & advice, not sale of items.
- Discretional purchase of equipment by carers would still be through local suppliers so conflict with commercial sector avoided; or through MASS which would link with the store.
- Store should supply equipment where indicated within a care package financial structure - loans for trials or for temporary or long term use.
- Store must have a cleaning and maintenance section (or agreement with local firm) so equipment is repaired as necessary, properly cleaned and ready for use.
- The need for aids may be urgent ie. patient incontinent. Carer told

apply to Service provider - delay, - service provider sends officer to visit home (extra to routine workers) for a paper work exercise & justification assessment - delay - paper work routed to office department for action - delay, - officer delegated to order equipment - delay, - Carer told 6 - 8 weeks delay in delivery time. Pathetic! This happened to me - about 3 months to obtain a few incontinence pads.

- If workers are in teams (see point a) Nurse should be able to see the need, justify it and get items immediately from the central store (within existing financial constraints).

- Nurse head of team should be able to demonstrate use of much equipment but community physiotherapist or occupational therapist should be called as necessary.

- Post of physiotherapist & occupational therapist should be moved from Community Centre & based with equipment store (or make extra posts).

- Information re useful aids + availability helpful in early stages of on going care often not given to carer till critical stages reached because IHC worker lacks the knowledge & expertise. RN may not visit till serious problems have arisen. Carer needs all the help possible at the earliest possible stages (- refer point a).

A separate equipment section / store would reduce the administrative burden on Service providers re ordering & delivering aids so they could concentrate on better organisation & supervision of their employees.

- Funding for aids should be separated from funding for practical help (see point c).

c) Improve level of financial assistance, increase it but also reallocate funds.

- Care package EACH has fixed funding allowance per client. If aids are needed e.g. incontinence pads, cost is taken from funding so hours of physical help are reduced, so a costly item may drastically reduce help to carer and cause extreme stress.

- A patient may progress low care -> high care dependency -> nursing care. A Nurse's time is calculated to cost double that of an IHC worker so

20 hours of help may now be reduced to 10 hours, at a time when the hours are needed most; even with greater expertise 20 hours work may not necessarily be completed in 10 hours just because a more skilled worker is doing the work. Change this system.

- Separate funding for aids from hours of practical assistance.
- Put people to work in teams (see point a) so skill level available is used to best advantage to meet patient's needs & at the same time train workers.

Allocate funds so availability and standards of respite care centres can be reviewed, including educational attainments of employees in day care and inpatient facilities. Instigate update training schemes. Review availability re geographical location, population density, accessability, transport costs.

Direct the care service providers who run a car pool to purchase some vehicles with a hydraulic lift so wheelchair users can be catered for more easily. It would help to prevent back injuries for employees lifting wheelchairs into car boots and help patients who have difficulty or can no longer get into a sedan car. Taxis with hydraulic lift for wheelchairs are available but not abundant; the demand is high during periods when disabled children are being taken to & from school. The Taxi subsidy scheme is excellent but travel costs are still high, hydraulic lift vehicles with Care Service providers would help to ease the situation i.e. free within care package limitations.

A scheme is needed to give carers superannuation payments or an enhanced pension or some allowance payable on retirement or cessation of caring period, as many carers are unable to gain employment & work for a financially secure retirement.

Some small but valuable financial relief on the weekly budget could be given by paying a hygiene/cleaning allowance, given either by supplying items from store (see point b) or giving shopping vouchers.

There is increased use of cleaning/washing products - washing bed linen

and personal clothing more frequently, cleaning equipment, sterilising items such as bed pans and urinals, cleaning food and body secretion spills.
Suggested items issued from the store (limited choice) soap, clothes washing powder, cleaner for ceramic surfaces, sponges, dish cloths, floor cloths, napisan or similar soaker for faecal contamination on clothing, disinfectants.

Although there is a safety net ~~and~~ some people do not qualify for concessional rates; drug/medicine costs are still high & many items are not covered by the PBS scheme; perhaps an additional allowance could be given for those on Care packages, increased with high care dependency.

d) Improve information availability re sources of help.
Establish one permanent post fully staffed 24 hours a day, every day, at each Centrelink office, person to act as an information resource centre for all matters relating to Aged Care - advertised as an information relay referral station. This person should know where responsibility lies; which section of the health/social welfare system should be approached to help with each kind of problem. Carers in stress do not know whom to contact especially in acute episodes. I have frequently been phoned by people when some untoward event has occurred & asked from whom person should seek help. People with little familiarity with the health care system find it difficult to know where to turn. In panic carer may phone:- hospital, ACAT, ambulance, community health centre, Care service provider, GP, charity organisations, CHIPs nurse, Red Cross Aids department, continence advisor, police, advocacy service, etc. etc.
Carer should be able to telephone Centrelink resource information person 24 hours a day and be given a quick, correct, definitive answer. At present caller may be referred from department to department, back and forth without finding the responsible entity; endless phone calls may be made in this way, very frustrating for the carer.

Carers wish to know their rights; where responsibility lies and the extent and limitations of care packages. Criteria should be agreed so that whichever service provider is giving a service of care a similar level

of care can be expected. Because a person is a veteran the care provided should not be greater or less than for another with an equal disability or care need. Care packages need to be standardised & equated regardless of which Ministry is providing the funding.

e) Improve transport availability & support costs.
already addressed under section c).

f) Clarify help availability should a natural disaster occur - flood, bush fire etc.
In the event of a natural disaster:- flood, cyclone, tsunami, bush fire, landslide, earthquake people "ageing in place" would need help. Direct Regional City Councils to formulate plans on how affairs might be managed for the sick and disabled being cared for in their homes and make the arrangements known to carers. Be clear about the responsibilities of care service providers versus other emergency services. Consider incorporating preparation for evacuation training in training courses for all people in the field, an extension to the "fire training" that IHC workers undergo at present.

g) Appoint a 'social link' organiser in each area.
There are many organisations / clubs / societies / churches which have members who are people of good will who are ready to give their time on a volunteer basis to help in various ways those in need in the community. Carers and the frail elderly become isolated and may not be in contact with such groups so do not know of help that would be of value to them, e.g. there is a Budhist group in this area from which members will go and sit with a dying patient, day or night during the last 1-2 weeks of life; not doing nursing duties but giving respite for a stressed carer. People do not all die in hospitals. There are other groups whose members will make telephone calls or do personal checks on frail elderly people especially those in early stages of dementia thus lessening demands on care service providers who cover physical aspects of care. There are people who mend wheel chairs without charge to the carer; but unless a carer knows such opportunities exist he/she

will not access them. These hours of help could be invaluable and at no cost to the government but the links must be made. Volunteer labour and support free but co-ordinated by a paid government official.

g) Government must allocate a larger vote to Ministry / Ministries copeing with present policy of "Ageing in Place".
Administration must be streamlined, co-ordinated and consolidated to limit beaurocracy and this must occur at Federal government level. Policies applicable nationally are required.

I note that Department of Families, Housing, Community Services and Indigenous Affairs is promoting a Government initiative as part of the National Action Plan on Mental Health: a Personal Helpers and Mentors Program; presumably a service similar to that provided for the physically sick in care packages. Also that a Commonwealth Respite and Carelink Centres information service has been advertised, no address given, I have not had occasion to access this.

Thank you for taking my views into consideration as part of the Committee's inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours sincerely,
Kathleen