

Challenges for informal carers in the context of dementia

Presented by Ailin Naderbagi for Jane Mears,
School of Social Sciences and Psychology,
Western Sydney University

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Apologies

- I am so sorry I am not here to present this paper. I was so looking forward participating and contributing to this conference working alongside like minded people with similar hopes and dreams- united in our endeavor to make the lives of older people, those with disabilities, and carers to create *A Caring World* (OECD, 1999).

Working together

- This presentation looks first at the still largely unacknowledged contribution of informal carers in sustaining aged care in Australia.
- I then look at the also largely unacknowledged contribution of paid care workers.
- I argue that aged care and home care, in particular, is a neglected and underfunded sector.
- I conclude by suggesting that we urgently need to support both informal carers and paid care workers, harness their experience, knowledge, and expertise of if we are to create a sustainable system of aged care and a caring society.

Informal Care

- 2.7 million Australians, aged 15 years and over were informal carers (ABS, 2015)
- Most of the care provided to older people and those with disabilities, is provided, unpaid, by informal carers.
- Informal carers have been pivotal in driving change, and the development of support and services for older people.

Informal Carers, Activism and Change

Informal carers, carers associations and researchers, have a long history of bringing our stories, into the public domain, translating informal caring, taking place in the privacy of the home, from a personal problem to a public issue.

Since the 1980s, activists and researchers have been documenting and analysing:

The costs of care, individual and social.

The lived experiences of informal carers, social isolation, emotional investment and the complex work of informal carers.

Juggling children and care for older people.

Juggling work and care

Informal Carers, Activism and Change

Carers carry large caring loads, and care at great personal cost.

Caring is complex and requires compassion, knowledge, understanding and skills, most particularly in the case of caring for those with a diagnosis of dementia- as our speakers in this session demonstrate.

Care Workers Supporting Informal Carers

What older people and informal carers want is flexible, relationship based, compassionate and reliable support in the home (and RAC) from experienced paid care workers.

Many home care providers have a long history and much experience in providing this care.

Most home care workers are skilled, knowledgeable and experienced in providing care in the home.

90% of care workers are older women (median age 55) who have a history as informal carers for older people (90%).

Care Workers (RAC and Home Care)

In 2016 there were 366,000 care workers in the aged care sector

RAC 236,000

HC 130,000 (20,000 less HC workers than in 2012).

These care workers provided care to:

925,000 older people (CHSP average 2 hrs per week)

90,000 people getting the more intensive home care support provided through HCPP - levels 1-4

In 2016, the median waiting time for home care services was 73 days, with 43 % of people waiting more than three months (Productivity Commission 2017, 14.14).

There is simply not enough support....

Build Sustainable Home Care Services

Informal carers need home care workers to provide support and sustain the caring enterprise.

- If we are to create a sustainable LTC system for older people, we need a skilled and well resourced workforce.
- Care workers are doing one the most important jobs in our society, and amongst the most poorly paid workers.
- Care workers are paid less than cleaners.

Conclusion

- Helen is so knowledgeable- and has overcome so many challenges, with grace and patience. The program she describes put in place by Baptist Care, could easily be replicated, utilising committed home care providers and working with care managers and care workers. We know that mentoring, as she describes, works, and we know that support groups are invaluable.
- There is excellent work being done- and we are certainly not timid in bringing forward our ideas. Social connectedness, social relationships... This is what we need to focus on. We are very good at this- working at the community level, to draw on each others strengths- support groups.
- We need to invest in the care workforce. Otherwise, with the current reforms and the continual moves towards greater marketization and privatization of care, the research indicates that existing inequalities will be exacerbated, with older people and informal carers, particularly those with few resources, are both missing out on care.
- We should not be expecting informal carers to continue to care at huge cost to themselves, or indeed for care workers (mostly older women) to paid minimum wages...
- We need to lobby for more funding and support for home care and informal carers are carrying a disproportionate burden of care.