



NSW

Carers

AUSTRALIA

# “Imagine a Health System without carers.....”

Title Carers Australia Submission to the National Health and Hospitals Reform Commission

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# Carers

- Carers New South Wales is the peak organisation for 750,000 people of all ages providing care for family members or friends with a disability, mental illness, chronic condition or who are frail.
  - There are 2.6 million unpaid carers in Australia:
  - The majority (75.6%) of carers are workforce age (18-64)
  - Almost seven percent (6.6%) of carers are under 18 years old
  - Over 65 year old carers make up 17.7% of the carer population
  - In 2005 unpaid carers provided an estimated 1.2 billion hours of care

# Carers

- Over 3 million people in Australia live with core activity limitations (ABS 2004)
- 79% of people with a disability who live in households receive care from relatives & friends, mainly partners or children (ABS 2004)
- 1.25 million people have disabilities that have profound or severe limitations (ABS 2004)
- 1.07 million people with a disability that has profound or severe limitations live in private households (ABS 2004)

# Carers

- 64% of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation (ABS 2004)
- Individual carers on average contribute 104 hours per week caring for a person with a mental illness
- It is estimated that carers provided 1.2 billion hours of unpaid care in 2005 (Access Economics, 2005)
- Annual replacement value of this care is estimated at over \$30.5 billion (Access Economics, 2005)

# Demographics

- Rapidly ageing population = more people require assistance due to age related disability
- Diminishing carer ratio over next 30 yrs from 57 primary carers per 100 people needing care in 2001 to just 35 primary carers per 100 people by 2031 (NATSEM 2004)
- Over next 30 yrs the number of carers projected to rise by 57% while the number of aged people needing care will rise by 160%

# Imagine a Health System without carers.....

The Carer Payment (child) Review Taskforce in its report to the Australian Government that was released in February 2008 stated....*"The caring role is one of immense social and economic value. It cannot be overemphasised that the care provided is often the difference between life and death."*



# Carers' experiences

*"After 12 months my father has not shown improvement and has been diagnosed with bronchiomalathia (this is a result of the transplant) just bad luck I guess! but to date there has been no case plan or care plan developed by the treating hospital, if there is we have not been told." (Young carer aged 17)*

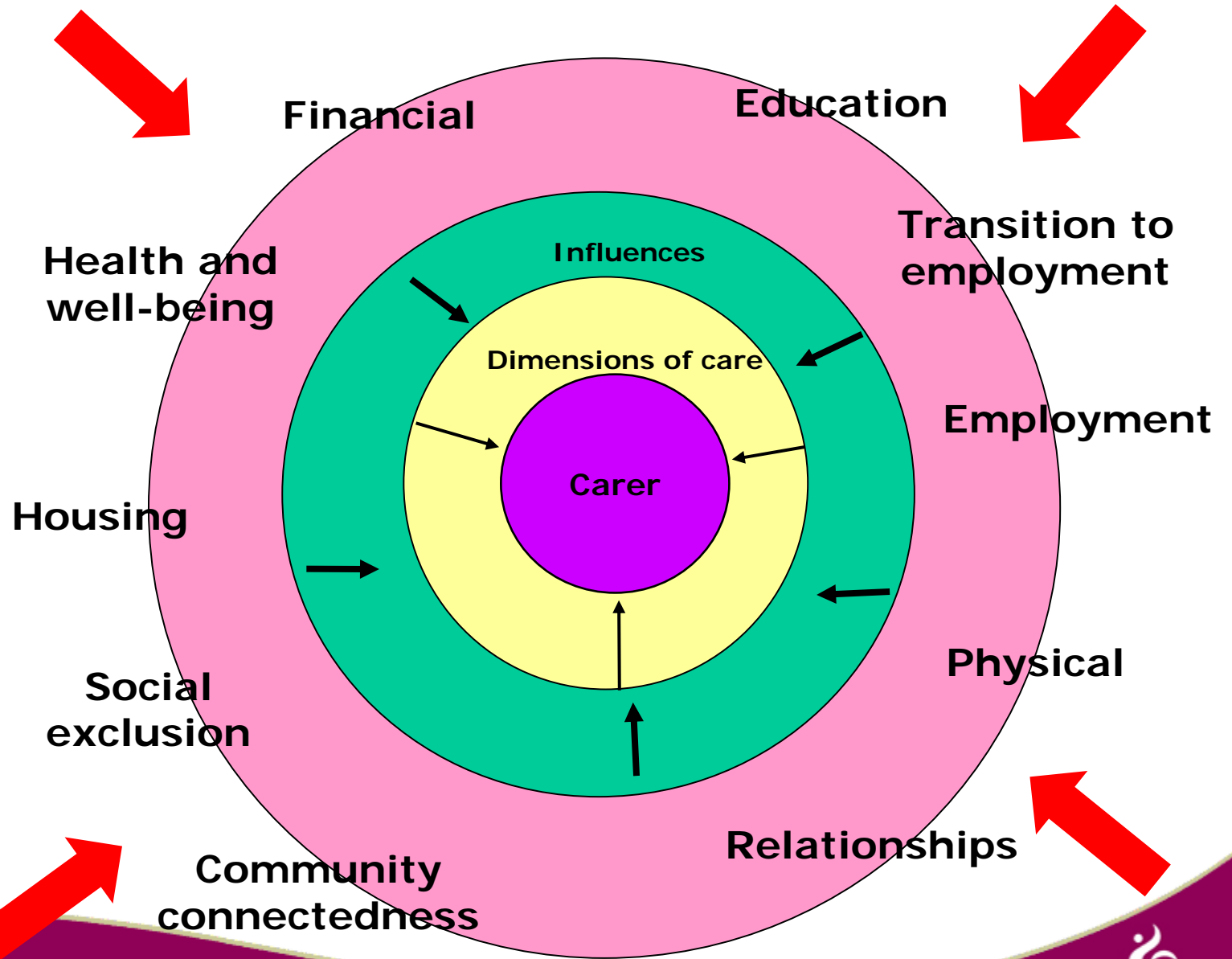
# Carers' experiences

- **'Wanting to be Heard and Included: Carers' Experiences of Hospitals"** Barrie O'Connor for Carers Queensland and published in Health Issues Journal, March 2007
- Carer's knowledge of patient overlooked
- Disagreements about discharge options
- Carer experience of premature release from hospital
- Cavalier manner of discharge – discharge plans 'worthless'
- Carer support and advocacy needed to navigate hospital system – 'shock'
- Unrecognised impacts of caring role
- Culture shift needed in hospital workers' views and treatment of carers

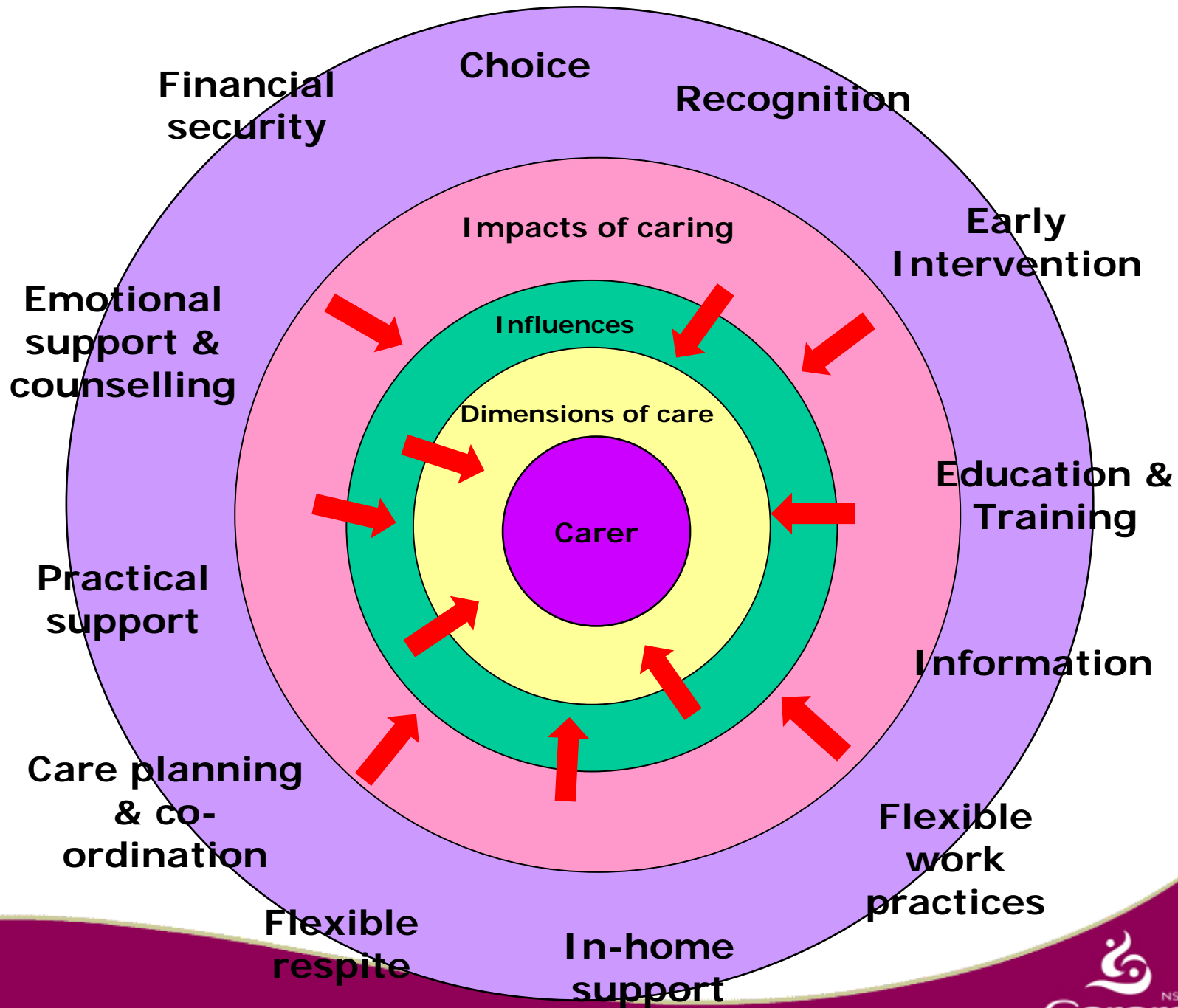
# Carers' experiences

*“There is no communication between treating public hospitals, my dad has been in our local hospital, because he was too ill to be transferred by road or air, his records also indicated possible kidney failure and the main Sydney hospital claimed that they were not aware of the entire situation, however my dad had been informed by the local hospital each time they had contacted Sydney”. (young carer aged 17 yrs)*

**Impacts of caring**



**Elements of carer support**



## What works well... (Carers QLD study)

- Carers in the Qld study identified:
  - Patient's hospital files located and up-to-date;
  - Patient known and welcomed;
  - Close links kept with GP; and
  - Carer views welcomed and their physical and information needs recognised

## What works well... (Carers QLD study)

- Carers in the Qld study identified:
  - At discharge, carers valued:
    - Getting a letter explaining the medical procedure, side effects, emergency contact no.;
    - Having discharge time convenient to carer needs; and
    - Having appropriate service supports in place

## **Ways to improve...** (Carers QLD study)

- Information kit for carers
- Carer contact person in hospital
- Carer ID card
- Discharge checklist – links with services implications for carers
- Training of all staff
- Continuity of case managers on discharge (MH)

# Carer experience

*A family lived with an adult son with schizophrenia, the son was quite disabled by his illness. The health service both in the acute care setting and community health setting, worked with and involved the family in the son's care.*

*The family strongly believe this assisted the son to remain in the community and the family to feel supported in their caring role. This family felt this inclusion and support from the health service enabled them to continue their caring role through extremely difficult circumstances.*

*The person with schizophrenia now lives independently with support from their family, the health service and minimal disability support service.*

CNSW Support and Advocacy Worker

# NSW

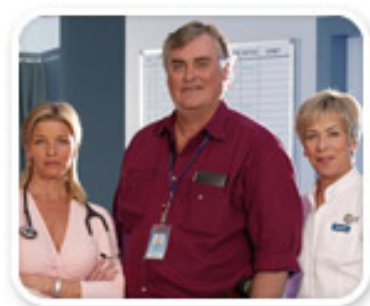
- NSW Carers Action Plan 2007-2012
- NSW Carers Program
- Carer support officers in AHS
- Family and Carer MH program

# Recommendations to National Health & Hospitals Reform Commission

- Governments formally acknowledge carers as essential partners in the health care system
- Carers be represented on all key health advisory groups
- Carers have access to ongoing, nationally consistent, training, education, information & resources
- Training & education for health professionals include carer modules

# Recommendations contd.

- Carer research be undertaken to inform education and training policies for health professionals and carers develop best practice models of service delivery, inform long-term planning and mapping of primary health care frameworks and provide governments at all levels with data to develop support programs for carers
- Investment in carer capacity and wellbeing be a priority for government at all levels.



# Ethics of Caring

*Who Cares? The Ethics of Caring in a Good Society:  
national conversation, national action*

- What ethical challenges might we as a society face to meet the changes in the needs of both the cared for and those who do the caring?
- Join the on-line 'Who Cares?' National Conversation  
6 September to 31 October 2008 [www.ethics.org.au](http://www.ethics.org.au)

A project of Carers NSW, St James Ethics Centre and  
Macquarie Group Foundation