

Carers NSW

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*Expansion of the Carer Life Course  
Framework*

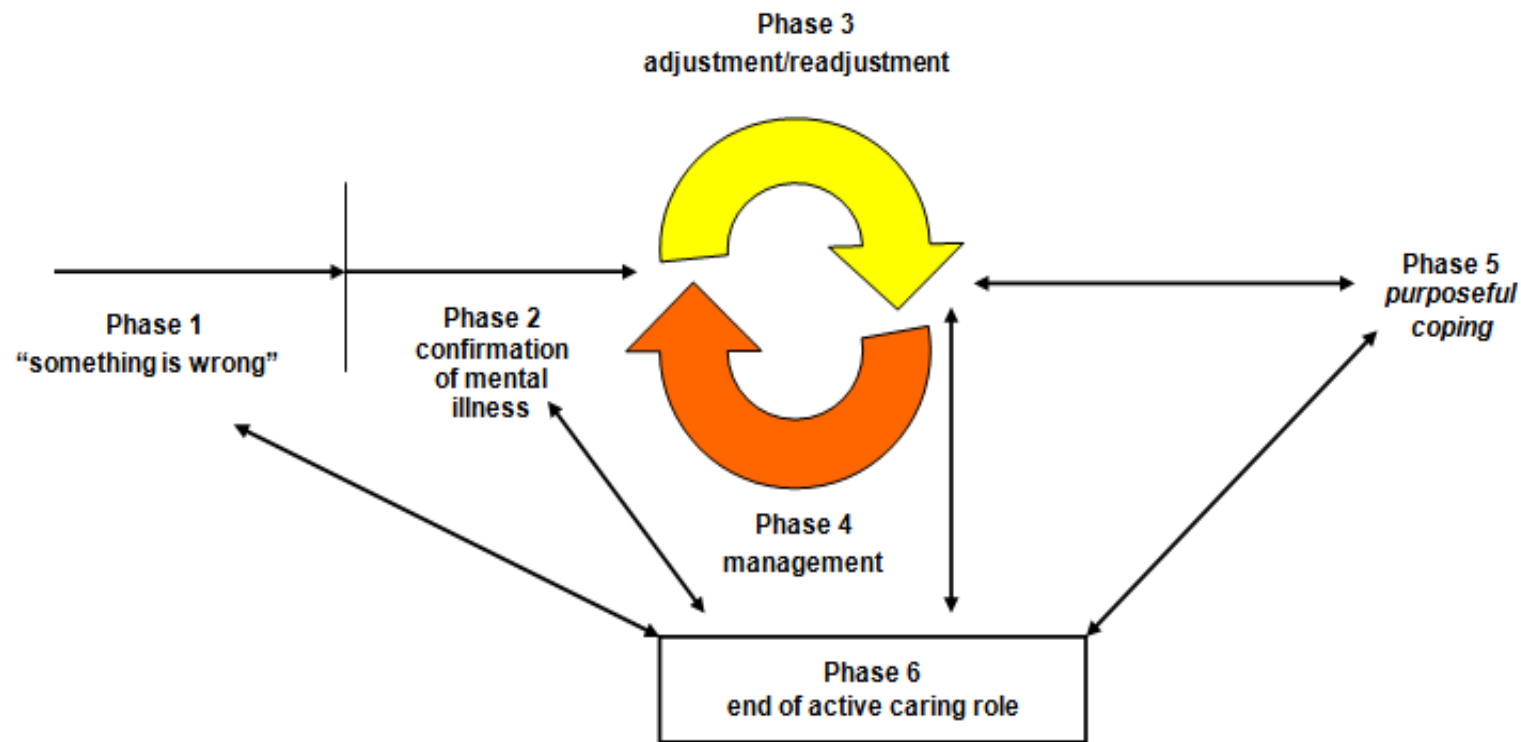
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# Carer Life Course Framework



- Published in 2005
- Allow development of a system of interventions and supports
  - Time
  - Place in life course
  - Relationship to person w/mental illness
- Based on carers' lived experiences

FIGURE 1. ORIGINAL CARER LIFE COURSE FRAMEWORK



**Constants across the phases**

- impact of the consumer's degree of wellness on the carer's well-being
- impact of the carer's other relationships on his/her well-being
- ongoing grief and loss
- ongoing need for support
- impact on financial resources
- need for carer's input to be heard
- fear about consumer's safety
- worry about what will happen when carer is gone
- impact of stigma
- fear about carer's own safety

**Variations**

- relationship to consumer
- life course/life stage
- context/resources available

# Impact of the framework



- Normalisation of carers' experiences
- Provides hope
- Useful to individual service providers
- Audit tool for mental health services
- Evidence for advocating for better supports
- Relevant for policy

# Key question

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- Could the Carer Life Course Framework be made into a generic instrument w/applicability to other carer groups?
- NSW Health provided funding to Carers NSW for an exploratory analysis

# Methodology



- Three different groups of carers
  - Parents of children w/a physical, sensory, intellectual or behavioural disability or developmental delay
  - Carers of people with cancer
  - Carers of people with an acquired brain injury (ABI)
- Focus groups and individual interviews
- Thematic analysis

# Participation



- 3 focus groups (15) + 4 interviews with parents of children w/a disability or developmental delay
- 1 focus group (6) + 2 interviews with carers of people with cancer
- 1 focus group (5) + 3 interviews with carers of people with an acquired brain injury

# Findings



- Overall structure of the framework fit well with all 3 groups (eg. phases, carer needs, emotions)
- Carers viewed the framework positively
  - would have been helpful early on in their journeys
  - Phase 5 (purposeful coping) offered them hope

# Consistency in types of supports



- Clear & easily available information
- Assistance in navigating the system
- Opportunities for appropriate education, emotional support, counselling when necessary
- Information about practical assistance
- Recognition of the importance of carers' role
- Encouragement/opportunities for self care
- Need for assistance in reaching phase 5
- Normalisation of their experiences

# Parents of children w/disabilities

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- Phases/constants fit well
- Particular issues
  - “ageing” out of services
  - transition points
  - felt “punished,” not rewarded by system
  - social isolation from other families
  - feeling like a failure for asking for help
  - difficult to take time out for selves
  - assistance in assessing treatment options
  - how to maintain hope while being realistic

# Carers of people with cancer



- Phases/constants fit well
  - screening vs investigation of symptoms
  - traumatic nature of diagnosis
  - entry into “cancer” system
  - cancer becomes the focus
  - fear, grief, loss, anger, guilt common
  - movement into phase 5 requires help
  - opportunities for advocacy
  - end of active caring through remission or bereavement

# Carers of people with cancer



- Specific issues/challenges
  - cope w/emotional journey of the person with cancer
  - long-term impact of treatment
  - uncertainty during remission
  - some felt that seeking help for themselves was a betrayal of the person with cancer
  - need skills to assess complementary and alternative therapies

# Carers of people with ABI

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- Treatment/rehab process
  - Accident/injury, hospitalisation, rehab, community re-entry or long-term care
- Phases fit well (w/exception of phase 1)
- Specific issues
  - uncertainty/reality of long-term situation
  - ongoing grief and loss
  - stigma
  - need help w/impacts of the injury
  - help w/legal, insurance, respite, & own needs

# Conclusion



- Exploratory analyses demonstrated that a generic framework can be constructed
- Future work needs to focus on:
  - Adjustments needed (particularly around constants/re-titling some of the phases)
  - How to best facilitate access to the material for carers, health professionals/service providers, services, NGOs, gov't agencies, policymakers

# Thank you

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- Carers NSW
- NSW Health
- All of the carers who participated in the focus groups and the professionals who helped recruit/organise