



# From Rehabilitation to Recovery: *A model to optimise consumer and carer involvement.*

Collaborative project: The University of Melbourne and St.Vincent's Hospital, Melbourne. Australian Research Council Linkages Grant.

Chris Graven, December 2008

## Contentions:

- Transition from rehabilitation to residing and participating in the community
- Health related QoL
- Post-stroke depression
- Goal setting
- Carers

## Carers

- 'After initial hospitalisation and stroke rehabilitation, 80% of stroke survivors return to the community relying on their family members' emotional, informational, and instrumental support for daily living' (Anderson et al., 1995)
- An increase in the prevalence of stroke is producing a resultant increase in the pressure on families to adopt the role of carers, and that this understudied issue requires greater attention in research in order to steer future policy and practice. (Han & Haley, 1999)
- Social support is a robust predictor of post-stroke functional ability (Kwakkel et al. 1996)

## Carers:

- Involvement of family, carers, and social networks in the rehabilitation process – with particular consideration to future burden of care status
- In a review by Han & Haley (1999), carer depression ranged from 32%-54% (Nb: different measures / timepoints from stroke impairs cross-comparison)
- Minimal studies looking at: Carer QoL, and interventions to affect carer outcomes
- No detailed studies found investigating alteration to carer community participation rates

## Purpose of current project:

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- To investigate the efficacy of interventions aimed at promoting goal achievement in the first year after stroke, in order to minimise depression and improve quality of life in both participants and their carers.

## Research design:

- Randomised controlled trial, with blinding of assessors at pre and post-intervention evaluations. Longitudinal design.
- Inclusion criteria
  - inpatient of the Rehabilitation Units of STV with a primary diagnosis of stroke (Kew and Fitzroy campuses)
  - primary carers of the participants
- Exclusion criteria
  - discharge to nursing home
  - living > one hour travel from STV
  - still inpatient > 6 months post-stroke

## Research questions:

- 1° hypothesis: that an integrated approach to facilitating goal achievement in the first year after stroke will result in less depressed mood in the participants who have had a stroke as compared to the participants receiving usual care.
- 2° hypotheses: that the integrated approach will enhance levels of participation in everyday and community activities, and improve perceived quality of life.

## Research questions:

For the carer participants:

- 1° hypothesis: that an integrated approach to facilitating goal achievement in the first year after stroke will result in a better perceived quality of life.
- 2° hypotheses: the integrated approach will decrease perceived burden of care and lessen the incidence of depressed mood.

## Group Allocation:

- Informed Consent (patient / carer)
- Random assignment into one of 2 groups (with stratification based on admission FIM scores → Mild / Severe):
  - Control Group
    - usual post-discharge care
    - phone contact at 2 & 6 weeks post-discharge (scripted, non-specific enquiries)
    - formal assessment at 6 & 12 months

## Intervention Group

- goal directed, integrated approach
- goals are communicated to the relevant post-discharge services (such as RITH / CRC / GP)
- provision of written information (NSF booklet about long-term stroke recovery / NSF fact sheets / local resources / websites / stroke and carer support gp)
- scripted phone contact 2 & 6 weeks (min.) to discuss: progress towards goals, current mood, informal supports, any need for more information, and any assistance that may be required (Flags).
- appropriate resources sought
- review at 3 months (Home Visit)
- formal assessment at 6 & 12 months

## Outcome Measures

	FIM	MMSE	GDS	SUPPH	GAS	AQoL	LHS	ACS	Zarit
Adm	★								
D/C	★	★	★	★	Devised				
6 mths	★	★	★▲	★	★	★▲	★	★▲	▲
12 mths	★	★	★▲	★	★	★▲	★	★▲	▲

Patient = ★ Carer = ▲

### Other measures:

- Review of perceived usefulness of the written information (snapshot at 3 mths)
- Record of rehabilitation and community resources that are utilised (calendar / contacts)
- Record of interventions by researchers (type / time taken)

### Participant numbers:

- Aim is to recruit 192 participants

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It is hoped that the results of this study will lead to the development of a model of care that can be utilised by health professionals to improve outcomes for people who have had a stroke and their associated carers.

***It will also contribute to the evidence base on the contribution made by carer involvement in the rehabilitation process on outcomes in stroke recovery***

## Considerations:

- Degree of 'deception' – all patients will be contacted post-discharge
- Main data of interest is 12 months post-stroke
  - significant length of time between phone calls and data collection
- Concerns re perception of support to Control group during these phone calls
  - rescripted / revised questions
  - no messages left
  - contacted by unknown researcher

## Qualitative component:

- A qualitative study (focus group) to gain patient and carer perspectives regarding local health service provision post-discharge from inpatient rehabilitation.

Exploring factors that assist recovery, or conversely present as a barrier to recovery.

n=16 (8 people who have had a stroke, and 8 carers)

- STV HREC-A approved