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ISSUES IN THE TRANSITION FROM HOME TO RESPITE DAY CARE

Professor Andrew Robinson

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Funding



This project was jointly funded by the
Tasmanian Government
and
Australian Government
through the
HACC program


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Background

- Respite care aims to alleviate carer stress and burden
- Range of benefits for family carers
- Respite care reported as being under-utilised
- Stigma and facing an 'uncomfortable realization
- In Tasmania concerns with people are referred but refuse to attend or attended only once or twice



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Methods

Part of a larger study involving:

- Audit of 10 day respite centres in southern Tasmania
- Focus groups with day respite staff
- Telephone interviews with carers


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Telephone interviews:

27 interviews conducted –

- 10 with carers whose family member refused to attend day care
- 17 with carers whose family member attends day care.
- 78% of respondents female
- Most participants caring for a spouse

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Results

1. Getting the right information

- Process was confusing
- Sheer volume of information proved overwhelming

2. Feeling unsafe as a barrier to attending

Feelings unsafe presented a barrier to accepting respite day care

Leaving home comforts

Reluctance to leave the security, comfort and familiarity of home

'it's a fear that he's got...he has just got it into his head that the only safe place to be is at home where everything looks familiar'

'leaving home is more fearful to her than dying or being ill'

Potential for humiliation

Family members feared possible humiliation attending respite day care

- *'fears other clients'*
- *'thinking he's a dill'*
- *'noticing she is forgetful'*
- *'being worried that she might not look as good as the others'*

Potential for humiliation (cont.)

In a small regional city, concern with 'embarrassment' if clients at centre were people that they had known or worked with

- *'she would feel embarrassed if any of the ladies from her card club saw her there'*
- *'he keeps saying he will see people at the centre who he worked with and that stops him going'*

3. Reacting to refusal to attend

Carers reaction to refusal ranged from acceptance to frustration and despair

Acceptance

Despite recognising need for a break, carers generally accepting of a refusal to attend

- *'not wanting to be too pushy',*
- *'I wouldn't want to force her to go'*
- *'I'll just have to wait'*

Acceptance (cont.)

For long term spouse - sense of betrayal


'I don't want to push her into going somewhere she doesn't feel comfortable'

Give into a refusal as a way to avoid conflict

'he gets nasty when I mention it, really nasty'

'he feels like I'm trying to dump him off somewhere so I can't even talk about it'

Carers were adamant that the centres were not at fault



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Frustration and Despair

Carers expressed frustration at their situation

'I am so fed up with the whole situation. I don't know how to convince him that it would be a good thing. I don't think he will ever go'

'I have begged on my knees that he go to the day centre, but it makes no difference'

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Frustration & Despair (cont.)



Despair – sense of a bleak future


'it's too hard to keep going'

'I have no life anymore'

'I can't see any way out of it'

'Things are only going to get worse...life's a misery...no one can truly help...life's a misery...life's a misery...'



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Concern

Concerned about welfare of family member should they not be able to continue to care for them

'I'm always thinking into the future and what happens if I get sick? What will he do? He won't leave the house and won't socialise with anyone. Going to day care would help him get prepared for me not being around all the time...I worry myself sick over it'

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4. Helping to ease the transition to respite day care



Promoting feelings of safety and security


Important that family member feels safe during initial visits

'just holding her hand and making her feel less frightened'

'being in the background so he knew I was there'



'It was like taking a five year old to kinder for the first time. He didn't want me to leave him...'


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Range of other issues: Choosing appropriate clothes/missing the bus

'The big hurdle was getting the bus. He got very anxious about it because he worries he will be late. So we have to get up very early to make sure he is ready to go...sometimes he is ready hours before the bus arrives!'

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Not giving up

Most recalled family member initially reluctant to attend

'hated it at first'

'told me he's not going back'

'said they [i.e. others at the centre] were too old, even though she's 90'

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Firm stand resulted in continued attendance

'I've had enough, you have to go'...now he loves it of course'

'not giving up'

'keep pushing and encouraging [for the 'sake of] everyone's sanity'

Benefits of attending

Benefits for family member: Being around others

Opportunity for family members to socialise the greatest benefit

Benefits for carer: Having a break

Great sense of relief once respite day care became an established part of their family member's care

'quietly going around the bend' to 'now feeling so free for those few hours a week'

Conclusion