



Respite Care/Short Breaks: Sharing an evidence review from Wales and Scotland (UK)

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Short Breaks Research and Practice Development Group



Short breaks research and practice development group

- To date Wales and Scotland, though Interest in the UK is broad and connections are wider
- Closer links developing with ARCH over the past two years, initially via Don Williamson

Terms of reference drafted April 2017

- The purpose...is to support a culture of research and build research capacity across the short breaks sector
- The aim is to improve understanding of the role of short breaks and respite care and to help structure future research in ways that will help support continuous improvement in policy and practice

<https://www.sharedcarescotland.org.uk/resources/research/uk-short-breaks-research-practice-development-group/>

More about the research group

Started with an interest in developing more flexible, personalised short breaks provision

Shared Care Scotland

- Aims to improve the quality and provision of short breaks in Scotland. Offers services including events, publications, research reports, online directory, managed by **Don Williamson**

Research on carers outcomes in Scotland and Wales

- Research on carers outcomes in both Wales and Scotland over many years – **Diane Seddon** in Wales and **Emma Miller and others** in Scotland (*possibilities to compare/contrast with proximal/distal outcomes for caring dyads in ARCH framework*)

Diverse carer research work at the OU

- **Joyce Cavaye** – carer journeys, life after caring
- **Roseanna Ware** - carers and disabled children

Wider collaboration between research, policy and practice is central





Spoiler alert...

This research tells us as much about the gaps as it does about the evidence



Scoping review

- Funded by Shared Care Scotland
- Purpose: better understand the research evidence about short breaks/respite for carers = carer outcomes
- Published literature from 2000 onwards
- Review itself conducted by Diane Seddon and Louise Prendergast (Bangor)
- SBRPDG acted as a reference group and review panel throughout

- 63 papers - carers for older people

Various types of short breaks identified:

- Includes more traditional, day-care, residential care and in-home respite (most evidence here)
- Alternative breaks, including supported holidays and access to leisure and arts

Short break outcomes

Carer health and well-being

The most prevalent outcome in the research

- Improvements in carer emotional well-being (sense of freedom, peace of mind and relief)
- Enhanced sense of resilience
- Opportunity to attend to self-care needs
- *Retrospective necessity*

I initially found myself thinking, I'm the only person... the only one who can't do this, who can't get it right. But then, I began to realise that actually I was normal...they [the day center staff] helped me realise that it was normal to need a break...and after I accepted their offer...I could finally see that it works. (Phillipson and Jones 2012, 11-12).

- Research confirms that positive health and wellbeing outcomes for carers and the individuals they support are linked to the provision of *personalised* short breaks

Short break outcomes – flipside



Carer health and well-being

- Some research shows that short breaks deliver *only* positive physical *but not* positive emotional outcomes (King and Parsons 2005), whilst others conclude that *any* positive benefits accruing from a break soon dissipate (McNally 2013).
- Research confirms that some carers taking short breaks report feelings of guilt, anxiety, emptiness and loneliness, particularly when the break takes the form of residential respite care, as well as sadness at being separated

....guilt. I didn't sleep that night hardly any at all and in the morning I got up andcancelled. (Strang 2001, 78-79).

- Negative effects mitigated when carers supported to accept their need for a short break as legitimate and appreciate its preventative effects

Short break outcomes

A life of their own

Supporting a life alongside caring is a key policy priority across the UK regions

- Opportunities for time away from the 'caring world' to pursue personal interests
- Thinking and relating to others in ways not linked to the caring role enables *temporary disconnect* from caring to focus on other roles (e.g. a grandmother, a wife) and *re-connect* with other family members/friends
- Short breaks afford opportunities to undertake routine domestic chores and mundane tasks, including shopping, but these activities may not be as beneficial as doing things that could not otherwise be done
- Use of short break time has a significant effect on carer outcomes - satisfactory use of time pursuing interests or being with family and friends is associated with positive outcomes and improved wellbeing

Short break outcomes

Positive caring relationships

- Short breaks:
 - play a key role in supporting positive caring relationships and enabling carers to continue caring
 - enable carers to positively frame their relationship with the supported person, their caring role and their achievements
- Nature and quality of the pre-existing relationship is important
- Gaps in understanding caring relationships as often reciprocal and the need to consider outcomes within dyads or other caring relationships

Important features of short breaks

- **Quality of the break** - experience for the supported person, in particular, the opportunity for safe and meaningful engagement, critically important in determining outcomes. Short breaks have greater benefit when appraised, by the carer, as a positive experience for the supported person. Indeed, research suggests this lessens carers' sense of guilt
- **Duration** - research confirms this is linked to carer reported outcomes, with longer breaks (over 24 hours) having a greater positive effect for carers than shorter ones. Research by Dundee Carers Centre (2014) suggests that a period of less than half a day is not considered a short break. Pienaar and Reynold's (2015) work supports this.
- We need to know more about changing outcomes over time

Scoping review – priorities for future research (and other developments)

Clustered around three key themes:

- 1. Understanding *what matters* - capture and evidence short break needs (personalisation, planning, conversation, restoration of identity, feelings of guilt etc)

Miller and Barrie (2019) Carer Outcome Recording article in BJSW
<https://strathprints.strath.ac.uk/69248/>

- 2. Capturing *what matters* - outcomes from short breaks (measuring outcomes, while retaining meaning, including process outcomes)

Cost-benefits, SROI, (societal level outcomes – ARCH) Diane Seddon

Meaningful and Measurable project, Emma Miller

- 3. Commissioning, delivering and scaling up alternative short breaks provision to reflect *what matters* to carers (commissioners as facilitators, picture building, incl diversity)

ARCH hosted webinar 9th December – Diane and Maria

Forthcoming report on Get Outside projects in Scotland

