Understanding unpaid carer break needs, break experiences, and break outcomes over the caregiving career

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A short break is any form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities. The purpose is to support the caring relationship and promote the health and well-being of the carer, the supported person, and other family members affected by the caring situation.

(Shared Care Scotland, 2023)

https://www.sharedcarescotland.org.uk/about-short-breaks/short-guides/
CARER

A carer is anyone who cares, unpaid, for a family member or friend who due to illness, disability, a mental health problem or an addiction, cannot cope without their support (Carers Trust, 2023).
Welsh Government Strategy for unpaid carers

Priority one: Identifying and valuing carers – all carers to be valued and supported to make an informed choice about the care they provide and to access the support they need whilst caring and when the caring role comes to an end.

Priority two: Providing information, advice and assistance – it is vital all carers have access to the right information and advice at the right time and in an appropriate format.

Priority three: Supporting life alongside caring – all carers must have the opportunity to take breaks from their caring role to enable them to maintain their own health and well-being and have a life alongside caring.

Priority four: Supporting carers in education and the workplace – employers and educational / training settings should be encouraged to adapt their policies and practices, enabling unpaid carers to work and learn alongside their caring role.
AIM

To explore and describe how carer short break needs, experiences of accessing short breaks, and desired short breaks outcomes change over the dementia caregiving career.

Identified knowledge gaps and priorities for future short break practice development:

• Short breaks for carers: a scoping review (Seddon & Prendergast, 2019).

• Research priorities in family caregiving: process and outcomes of a conference on family-centered care across the trajectory of serious illness (Harvath et al., 2020).

• Making personalised short breaks meaningful: a future research agenda to connect academia, policy and practice (Seddon et al., 2021).
THE CAREGIVING CAREER

Originally defined by Aneshensel and Pearlin in the early 1990s.

• Construct of the ‘Caregiving Career’ used to emphasize the evolving character of caregiving:
  “The transitions and changing conditions that carers experience during extended trajectories of their activities” (Aneshensel et al., 1995, p. xv)

• Caregiving is a dynamic and developmental process comprised of the transition through different stages.
Interviews with spousal carers for people living with dementia (2021)

Objective:

To explore personal stories of caregiving:
• the support carers received that helped them to care;
• the ways carers experienced short breaks from their caring routine and responsibilities.
• how short break needs and preferences changed over time.

13 conversations

Spousal carers:
• Age range 69 to 87 years
• Mean age 76 years

People living with dementia:
• Age range 66 to 94 years
• Mean age 80 years

Three people living with dementia were diagnosed with an additional neurological disease, and one had long-term physical disabilities. Three were bed ridden and being cared for at home.

All the families lived in North Wales
CARERS’ CHANGING SHORT BREAK NEEDS

Couples’ needs for breaks reflected their pre-existing routines and preferences

“We have been all over the country with tour company...we’ve met a lot of people over the years. You get a full cooked breakfast in the morning, and you get a three-course meal at night...I don’t have to drive.” (C5)

Needs for breaks were to continue to nurture well-being through activities, friendship, and reciprocal support

“The most important thing in my month was the day at carers club, because you got to share your problems and find out information and know you are not alone...Just having a day with other people in a similar situation that was the best part.” (C1)

Longer and more consistent breaks were needed for carers to recuperate from their caring role

“It was only two hours once a week, that is not a lot out of 24 hours, when you have the other 22 hours to do...it would have been nice if I could have just gone on holiday for a week.” (C13)

The need for breaks continued after the person with dementia moved to a care home

“Even though he’s in care, I’ll never stop caring. He phones me a thousand times a day...in the night my head nearly splits...Since he's been in care, I go every three weeks to have a facial, body massage, pedicure, manicure, and I do feel an immense physical relief from that.” (C11)
CARERS’ EXPERIENCES OF ACCESSING SHORT BREAKS

Community activities, that were either dementia specific or inclusive groups that welcomed people irrelevant of diagnosis, were perceived by many carers as an accessible, inexpensive, and consistent way of supporting regular breaks, with the added value of peer support.

Carers grew uncomfortable leaving their partner by themselves at home, or their partner exhibited distress in the absence of the carer, achieving a break became more difficult and required more planning and organisation.

Carers tried to seek more practical support and guidance from health or social care professionals to experience a break. The immediacy of this support was paramount to ensure access to a timely break.

“I looked into the kind of dementia activities, and there were loads, places I could take him and leave him for a morning which would help me have a break.” (C3)

“The local authority will say, ‘we have this service and this service’ but, when you dig into it, they aren’t available either through lack of staff, lack of money, or the ridiculous high criteria” (C6).
Despite being given information about break options, the lack of guidance to make sense of the information and talk through options meant carers struggled to think about how their break needs could be met.

A typical arrangement to facilitate weekly short breaks for a few hours was through in-home break provision.

“I feel I get bogged down with all the information and trying to take it all in... people seem to link you all together as though you are the same, but dementia doesn’t affect everybody the same.” (C8)

“Communicative tensions were present between couples which made some carers feel guilty about articulating their break needs and taking a break.”

“I enjoy having [paid carer] in the house, I can go out during that time, but I love [paid carer’s] company too much I often stay in, it’s also company for me...we have good rapport, all three of us laugh together, and that is good therapy for me”. (C3)
CARERS’ EXPERIENCES OF ACCESSING SHORT BREAKS

As caregiving demands escalated, a sufficient day and/or night rest was crucial for carers. Carers frustratingly reflected upon the limited choice and availability of break options for them to experience a full day for themselves.

Challenges were experienced in finding highly skilled and dedicated care staff to become part of a caring team, which would allow carers to take regular daily breaks.

“We have been struggling to get the amount of care that [wife] should be having, it’s so difficult to get a good carer...that is one of the main difficulties, finding suitable carers who you know and trust.” (C9)

“We tried to get him to go to the day centre...a couple of times when [husband] was more in the mood of getting in the wheelchair, and then he’d back off at the last minute and he wouldn't go.” (C5)

“As their partner become less physically mobile, carers conveyed their concern over limited activities that provided meaningful engagement for the person with dementia.”
CARERS’ SHORT BREAK OUTCOMES

A break supported meaningful outcomes when it enabled carers to nurture the aspects of their well-being that mattered most, at that point in their life. This could be solitude or time with their partner but in a new environment that offered a pleasant change from caregiving routines.

- Carers valued having the time to do as they please, without expectation or pressure.
- Increased compassion, energy to be in the present moment with their partner, and patience to communicate with empathy.
- Carers appreciated the consistency, respect, and ability of the professional carer to support the personhood and interests of the person with dementia.
- Caregiving partnership with professionals, cultivated through trust and mutual understanding. The sense of security and confidence underpinned a meaningful break experience and outcomes for everyone involved.
WHAT DO THESE FINDINGS TELL US?

• A range of short breaks of varying lengths, appropriate supports, and activities were sought throughout the caregiving career to promote well-being and help sustain the caregiving relationship.

• Each relationship had pre-existing strengths and vulnerabilities to the challenge of dementia that influenced the couple’s ability to adjust, and carers’ short break needs and preferences, and desired outcomes.

• The process of deciding upon a break was typified by many deliberations and the balancing and negotiation of personal and relational priorities, needs, preferences, and opportunities.

• The career trajectory was marked by the gradual transition from informal community activities, characterised by health promoting activities and social engagement, that provided a break, to formal break services with increasing support from health and social care professionals.

• It was in these transitions where delay through lack of accessible and relevant information, supported choice from practitioners, and lack of choice of break options, caused difficulties for carers to access timely breaks.

• A subtle shift in the priority of short breaks can be discerned, from earlier in the career where supporting relational well-being and couplehood was the priority, to later in the career, where greater emphasis was placed on breaks to enable carers to rest and recuperate from their caregiving demands.

• The need for breaks continued after the person with dementia moved to a care home.
The temporal and changing nature of carer short break needs and preferences underlines the importance of the assessment review process to ensure continued relevance of support, including the outcomes supported through short breaks. State of Caring Wales report (2022) found only 19% of carers in Wales reported that they had an assessment, or a review of their assessment, in the last 12 months.

Importance of consistent practitioner support. A single expert contact for carers who can offer bespoke and curated support throughout their career. Coordinate short breaks alongside others forms of support.

In north Wales these roles have been identified as a ‘Carers Well-being Officer’ or ‘Carers Champion’, and in the context of dementia caregiving relationships ‘Dementia Connectors’. How they work alongside other professionals (e.g., Dementia Support Worker, Social Worker etc.) requires further attention to avoid role duplication or confusion.

The availability of suitably qualified and skilled care staff is central for carers and people with dementia to realise meaningful short breaks outcomes. Ongoing work in Wales is being delivered under the Workforce Strategy for Health and Social Care which outlines the strategic framework, ambitions, and actions to develop a more engaged, agile, skilled, and sustainable workforce by 2030 (Social Care Wales, 2020).
Carers are not always in a position of stability or clarity to feel empowered to, or have the solutions or resources, to identify their own break needs without support and guidance.

The practitioner must be equipped with a wealth of information and knowledge about local services and support and skilfully explore resourceful options that can support short break; this is creative and complex interpersonal work. Requires confidence to think about breaks in their broadest sense, e.g., as a service, an activity or an item.

Impartial relational support offered by practitioners to legitimise carer’s need for and right to breaks, and ease associated anxieties. For breaks taken apart carers can experience guilt or anxiety.
TOWARDS A CONCEPTUAL FRAMEWORK FOR SHORT BREAKS

Short breaks have potential to extend across the whole course of the caregiving career, so their benefit is cumulative and sustained (Bangerter et al., 2019; Gaugler et al., 2003; Liu et al., 2015; Måvall & Malmberg, 2007; Zarit, 2018).

The All-Wales Dementia Pathway of Standards is structured around the ‘journey’. People with dementia and their carers should be offered stage appropriate learning, supports, and services (Improvement Cymru, 2021).

However, there is no reference to how many stages typify a journey, what distinguishes a stage, and the transitions between them.
Scoping review of published literature identified eleven models of caregiving in dementia in which discernible stages were described.

Stage is described as:

“A heuristic device that helps detect the threads connecting each part of caregiving to its other parts and identify conditions that move caregivers along their career trajectories at different rates and at different psychological and material cost to themselves” (Aneshensel et al., 1995, p. 23).

- Models were developed in USA (4), UK (3), Canada (2), Chain (1), Japan (1).
- Stages within most models capture the varying challenges that confront carers, involving practical caring tasks, stressors, and emotional states.

Can these models offer insight into short breaks most appropriate to stage and how short breaks might support carers as they transition through stages?
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<td>My spouse has dementia</td>
<td>Monitoring initial symptoms</td>
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<td>Mental stress</td>
<td>From spouse to caregiver</td>
<td>Navigating diagnosis</td>
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<td>Physical burden</td>
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<td>Assisting with Instrumental Activities of Daily Living</td>
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<td>Worries</td>
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Pfeiffer (1999)
- Coping with the initial impact of being told the diagnosis
- To be or not to be a caregiver
- At home caregiving. The long journey
- Caregiving during residential or institutional placement
- Death of the patient - grief and relief
- Resuming life - healing and renewal

Nolan et al., (1996)
- Building on the past
- Recognising the need
- Taking it on
- Working through it
- Reaching the end
- A new beginning

Aneshensel et al., (1995)
- Role acquisition
- Role enactment
- Role disengagement

Wuest et al., (1994)
- Dawning
- Holding on
- Letting go
THANK-YOU

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REFERENCES


