



Evidence at a Glance

Issue 3: Effective information support programmes for care partners

Welcome to *Evidence at a Glance No 3*. We hope that you are finding this research focused resource useful support for what you already do, as well as providing ideas on how to improve your service.

The [New Zealand Framework for Dementia Care](#)¹ recommends varied ways of delivering support for care partners including support groups, respite care, resources, education, home and community support services and grief support.

This issue focuses on the evidence for the effectiveness of providing information support programmes for care partners of people with dementia. The 2018 [NICE](#) Guidelines² note that carer support interventions are most likely to be successful when provided in groups

What information do support groups address?

Potentially there are many topics that can be covered in support groups. The NICE Guidelines² suggest education topics about:

- dementia, symptoms and changes;
 - developing personalised strategies and skills;
 - providing care and responding to changed behaviour;
 - adapting communication;
 - looking after personal physical and mental health and well being;
 - planning enjoyable activities to do together;
 - relevant support services;
 - planning for the future.
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Evaluation of the UK Alzheimer's Society Carer Information and Support Programme (CriSP)

The UK Alzheimer's Society's Carer Information and Support Programme (CriSP) is a long-established caregiver support programme developed in response to the expressed wish of care partners for information and support. There are 2 courses; CriSP1 (4 sessions) for

¹ Ministry of Health. (2013). *New Zealand Framework for Dementia Care*. Wellington, New Zealand: Author. Retrieved from <https://www.health.govt.nz/system/files/documents/publications/new-zealand-framework-for-dementia-care-nov13.pdf>

² National Institute for Health and Care Excellence [NICE]. (2018). *Dementia assessment, management and support for people living with dementia and their carers*. United Kingdom: Author. Retrieved from <https://www.nice.org.uk/guidance/ng97>

family and friends of a person recently diagnosed, and CriSP2 (3 sessions) covering the issues that occur over time.

The purpose of the CriSP Programme is to improve the knowledge, skills and understanding of people caring for people with dementia. It aims to provide efficient support and up to date evidence-based information.

In 2012 the UK Alzheimer's Society commissioned an independent evaluation of the programme³. The evaluation explored the impact of the courses on carers and relationships. The research team carried out 25 in-depth interviews with care partners aged 45-85. The people they cared for included parents, partners and siblings. Many (68%) lived with the person they were the care partner for.

Key findings

- Learning about dementia and how it developed was particularly valuable. The experiences of both group facilitators and other carers in the group were useful in helping to understand the person, how they were changing and therefore how to care.
- Hearing from and sharing information and experiences with others contributed to understanding, enabled reciprocity and provided feelings of support. Practical advice on how to respond to situations was useful and feelings of isolation reduced.
- Visual information was important – perceived to be more memorable.
- Written information and reference material was also valued. However, it could be difficult to organise this in easily retrievable form.
- Timing of information was critical and could add to families distress. *It was important to note and respond to the fact that people whose partners were in early stage dementia could be distressed when they heard about people whose partners were in later stages.*
- A difficult aspect of caring interactions with service providers was in accessing care support. Many carers felt that GPs often lacked knowledge about dementia. Care partners experience of community-based services were generally positive.
- The CriSP courses provided the care partners with knowledge about services and their legal and financial rights. After the courses they felt more confident in talking about what they needed for the person and to support them as carers.
- Most would have liked a refresher opportunity to reflect on issues in the light of their changing experience. Some were disappointed in loss of contact with the group members after the course finished.

³ Barnes, M., Henwood, F., Smith, N., & Waller, D. (2013). *External Evaluation of the Alzheimer's Society Carer Information and Support programme (CriSP)*. Brighton, UK: University of Brighton. Retrieved from [https://www.brighton.ac.uk/research-and-enterprise/groups/social-science-policy/research-projects/carers-information-and-support-programme-\(crisp\).aspx](https://www.brighton.ac.uk/research-and-enterprise/groups/social-science-policy/research-projects/carers-information-and-support-programme-(crisp).aspx) [Summary](#) (4 page) and [complete report](#)

- Carers valued the opportunity to consider their own needs and develop their own caring networks. This could enable them to feel less guilty about arranging other carers.

Conclusion

Overall the researchers felt the style of delivery of CriSP courses in providing information and the opportunity to mix with other in similar situations was valuable for the care partners. Care partners felt the courses enabled them to develop knowledge and understanding to care well for their partners in a more positive relationship. Experiential knowledge was just as important as specialist knowledge in developing families caring skills and strategies.

Questions to discuss:

Do we run regular group education courses for families?

If so

- What are the topics that are most appreciated?
- Do we provide “take-away” written resources?
- Do we provide refresher sessions
- Do we help care partners to set up their own support networks?
- How could we improve programme evaluation processes?
- What involvement is there from people living with dementia in the development of our education programmes?

If not

- What are the barriers to providing regular group education courses for families?
- Perhaps work through a Force Field Analysis (Lewin) to identify the driving and resisting forces to providing education courses – check out the [Quality Improvement \(NHS\) website](#) for more information about this exercise.