

Alzheimer's Society

Carers' Information
and Support
Programme (CrISP)



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CrISP

The beginning

The Carers' Information and Support Programme (CrISP) was developed following a review of research findings and a series of focus groups for carers and Alzheimer's Society staff in 2010.

This indicated that family carers wanted access to information as soon as possible after diagnosis and preferred printed information and guidance delivered face to face in an environment with peer support.

The Society undertook a three year programme of testing, evaluating and refining the model to reach the final programme.

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What happens?

Aims to improve the knowledge, skills and understanding of people caring for a person with dementia:

- Increase knowledge of dementia
- Improve access help and services
- Improve coping ability
- Help planning for the future
- Provide peer support and sharing

The programme consists of two separate parts: CrISP 1 and CrISP 2. Each programme is delivered to small groups of up to 12 people.

CrISP 1

Content

CrISP 1 has been designed specifically for carers, family members and friends of people with a recent diagnosis of a dementia. It consists of four essential sessions:

- Understanding dementia
- Legal and money matters
- Providing support and care
- Coping day-to-day
- Next steps.

CrISP 2

Content

CrISP 2 has been designed specifically for people who have been living with dementia for some time. It consists of three essential sessions:

- Understanding how dementia progresses
- Living with change as dementia progresses
- Living well as dementia progresses, including occupation and activities.

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Early findings and further development

Between October 2011 and March 2012 the programme was delivered by trained Alzheimer's Society staff across nineteen localities in England and Wales.

- 26 four-session programmes were run
- 244 carers attended at least one session

Demographics of participants

- 75% of carers were female and 25% were male
- 75% of carers were aged between 50 and 79
- 84% of carers supported someone over the age of 70
- 54% of carers were caring for their partner
- 37% were caring for a parent
- 9% were caring for a friend or those described as 'other'
- 74% of carers had been caring for over a year and 26% for up to 12 months

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Final internal evaluation - Method

Internal evaluation:

Three sets of questionnaires were completed by 244 carers

1. Initial questionnaire: completed by 195 carers before session one (87% of those who attended the first session).
2. Final questionnaire: completed by 160 carers at the end of session 4 (79% of those who attended)
3. Follow up questionnaires: sent by nine sites to 103 participating carers three months after session four. 67 (65%) carers returned questionnaires.

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Final internal evaluation - results

Results highlighted how CrISP met each of the six intended outcomes for the programme.

Outcome 1: Carers feel that they have increased knowledge of dementia

- At the beginning of the programme, only 2% of carers said they had a 'great deal of knowledge' about dementia.
- This increased to 64% by the end of the programme.

Outcome 2: Carers feel they have been supported to access help and services.

- At the beginning of the programme, 32% felt they had no knowledge about getting services.
- By the end of the programme, 64% of carers felt they had a 'great deal of knowledge' about getting these services.

Outcome 3: Carers feel they have been provided with practical information that they can use in coping with living with dementia day to day

- At the beginning of the programme, 21% felt that they had practical strategies to support the person with dementia. This increased to 62% by the end.

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Final internal evaluation - results

Outcome 4: Carers feel that they have received information and an understanding of how to plan with and for the person they care for, now and in the future

- Before starting the programme, 21% of carers said they had 'no knowledge' about planning for the future by arranging their money and legal affairs
- By the end of the programme 67% had 'a great deal of knowledge' about planning for the future.

Outcome 5: Carers feel they have benefited from peer support and sharing experiences

- 96% of respondents said they had found it 'very helpful' to share experiences within the group.

Outcome 6: Carers are provided with access to a forum where information is given in an understandable format

When asked what had been most useful about CrISP, the most frequently cited topic (46%) was the information content and availability of Alzheimer's Society factsheets.

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External evaluation results

CrISP has also been evaluated by Brighton University. The evaluation showed that carers valued the information and increased knowledge they received and the way that information was imparted in a supportive peer group environment where it could be explored with others.

- Carers felt it enabled them to develop skills and confidence in supporting the person they cared for.
- Experiential knowledge was valued highly by carers.
- The timing of information was critical
- The courses led carers to be more confident
- There was a less obvious impact on carers' capacities to secure support for themselves.

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The Future

Approximately 200 people accessed CrISP courses in June 2018.

We are now embarking on an ambitious programme to support other organisations to deliver CrISP to ensure even more carers are able to benefit.

This will see us develop training, resources and on-going support to enable others to deliver CrISP under the Alzheimer's Society trusted brand.

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The evidence from the evaluation and the experience and learning the Alzheimer's Society has gained through delivery of CrISP courses over the last three years would be of benefit to other countries interested in establishing their own carer support programmes.

We are willing to discuss our learning and how to establish CrISP approaches with interested parties.