

We Care – Representing informal carers, relatives and friends – Germany

**“wir pflegen” – Interessenvertretung begleitender
Angehöriger und Freunde in Deutschland e.V.**

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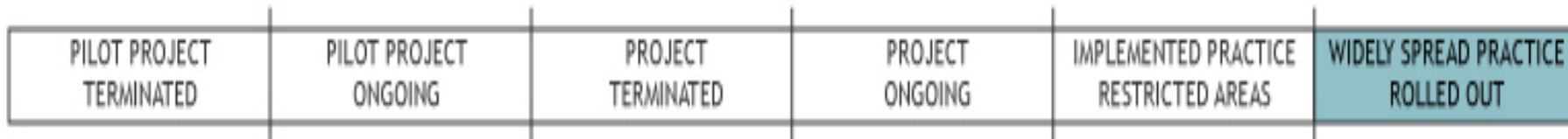
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Introduction: main objectives, key-issues addressed, status

- Realizing informal carers as the backbone of LTC
- Listening to carers' needs
- Actual situation when starting: The reform for the LTC Insurance in Germany was under development - an extraordinary situation for including carers' voices



Why was this project developed/implemented?

- EUROFAMCARE showed:
 - Gaps between needs of carers und their support
 - In some countries: carers' organisations brought the topic higher on the political agenda
- EUROCARERS - European Association Working for Carers was founded
- No organisation only for caregivers in Germany
- To develop an interface between carers and decision-makers

Main features of the example (description)

- To bring together initiatives on different levels to form a basis for a common voice of carers
 - of all ages
 - for all kinds of dependencies
- Lack of awareness of carers' needs at all political levels
- Work of **wir pflegen** is based on 11 Guiding Principles:
 - Recognition – Co-determination (participation) – Information - Equality of opportunity – Choice - Support – Health promotion and prevention - Compatibility of care and employment - Financial security - Time off - Social Inclusion

What are/were the effects?

- Bringing caregivers together to engage themselves for their own interests – but it needs time and patience
- Own homepage as a platform for external and internal exchange and position development
- Yearly workshops for the members
- Increasing invitations from high level political and societal initiatives to present carers needs and demands
- High interest of media – but: mainly for stories

Strengths and limitations

- **Strengths:**
 - Active volunteers fighting for the same interests / Cooperation between family carers and supporting others / International exchange, e.g. by co-operation with EUROCARERS
- **Limitations:**
 - Lack of infrastructure and financial support, but high expectations to the board / lack of time of caregivers to engage politically / different ideas about the speed of internal decision-making processes and new developments

Conclusions

- **For practice:** better co-operation between informal and formal carers, as they have similar or even equal aims / more exchange and co-ordination of initiatives between organisations working with and for carers
- **For policy-makers:** carers need quick changes, carers' organisations need support
- **For research:** hidden problems should become a topic, e.g. illegal support, risk of poverty, risk of career problems, risk of abuse / actual data are needed to show the growing danger for a care collapse