

# PALLIATIVE CARE CARER EXPERIENCE INFLUENCING SERVICE CHANGE



The action plan **Living and Dying Well** (2008) directed NHS Boards to identify carer needs as well as those of people with palliative and end of life care needs. Discussions in Lanarkshire led to the suggestion that carers might prefer this to be done via face-to-face interviews. It was proposed that carers with similar experience should lead these discussions and be trained to carry out interviews with other carers. This work is uniquely founded on carer experience and recognises that a palliative diagnosis extends beyond the individual to the whole family system. Support services therefore need to include the whole system, in particular the experiences of informal carers.

The reasons for this were that people with similar experiences:

- ❖ can establish rapport which affects the quality of the information gathered
- ❖ are likely to know what to ask, and how to ask certain kinds of question
- ❖ could be empowered to use their unique expert knowledge as carers

The initial reaction of carers from North and South Lanarkshire was that they had related their experiences many times in the past and did not perceive a need to do so again. However, when it was explained that this proposal was for carers to be trained to gather carer support needs, there was much more interest. North and South Lanarkshire carer organisations agreed to support a collaborative funding bid (between NHS Lanarkshire and the University of Stirling) which was successful. It is contended that there will be qualitative differences in the interviews because they are carried out by someone with a shared carer identity.



## Main components of the work

The four main aspects are to:

- ❖ Provide interview training for a small number of former carers of people with palliative care needs
- ❖ Support the trained carer interviewers to gather information on the support needs of current palliative care carers
- ❖ Provide full support during the training and interviews, including debriefing and emotional support
- ❖ Work with the carer interviewers to interpret the data gathered, which will help to inform service provision

## Progress to date

Most of the work carried out thus far has been in preparation for the main study, but the following have been completed:

- ❖ Initial meeting with carers who have expressed a wish to be trained to conduct the interviews
- ❖ Study design and methodology agreed with carers
- ❖ Ethical approval application completed and submitted

## Training course & materials prepared

We are currently awaiting the ethics committee decision, but once this has been received, the recruitment and training of carer interviewers can begin. This unique project is founded on the expert knowledge and experience of palliative care carers.

### FOR FURTHER INFORMATION, PLEASE CONTACT:

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