After a quick introduction to New Zealand and its cultural context, Merryn delivered a fascinating insight into recent research activities by Te Arai: the Palliative Care and End of Life Care Research Group based at The University of Auckland.

Merryn talked about different projects including identifying what was important to people at end of life from a recent longitudinal survey which highlighted the very complex role of carers, and how, for some groups, the spiritual needs were far greater than other issues, such as preferred place of death. This counters much policy rhetoric about what is important at the end of life.

Merryn then shared an action research project with carers who gave their stories, memories, photographs and video clips to be developed into short films about the complexities of their role. A clip from one of the finished films highlighted the perspectives of a male carer and importance of treating their family members as persons who are part of the family regardless of diagnosis.

Another project was undertaken which empowered the local Pacific Islanders population who decided to produce a song and music video about being a carer – a product that was not expected by the research team, but has proved very effective.

The final research project Merryn explained was for former carers to bring together their experiences into a publication of thoughts and reflections on the realities of caring for someone at end of life, in order to support current carers. This emotive and informative book is now being sold online and distributed locally.

Merryn’s research demonstrated how different communities devised different ways to answer the research questions of carer experiences, thereby raising questions about the need for different approaches in supporting carers from different communities and societies. The research also showed how working in partnership with participants can bring about unanticipated results which are truly participant led and maybe even more meaningful than predicted.