"Do you think we can manage?"

Palliative care for people with learning disabilities – education and training for staff in community care settings

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Background

Intellectual disability affects about 1-1.5 % of the Norwegian population. Affected individuals reach a higher age than before, having an increased prevalence of age related diseases and palliative care needs. The Intellectual Disability Services in Bergen, the Centre for Development of Institutional and Home Care Services in Hordaland County and the Regional Centre of Excellence for Palliative Care, Western Norway, have been running a three year project 2015-2018 to improve palliative care for this user group.

Aim

The overall aim is to offer people with intellectual disabilities optimal palliative care in their well-known surroundings (independent living arrangements). The objectives are to strengthen staff competence and improve cooperation between service providers.

Method

Develop an educational programme for staff members, offer follow-up and guidance, appoint local champions (resource staff), develop local guidelines, share experiences.



Results

Five municipalities have been included.

- Education: a course in basic palliative care over two half days has been developed and run 10 times for multi-professional staff representing 35 independent living arrangements (156 participants day 1, 142 day 2; 127 both days). Positive evaluations. Follow-up and guidance have been offered locally, but rarely used.
- Local champions: each municipality has appointed minimum two resource staff who have been integrated into existing regional palliative care networks
- Local guidelines: guidelines developed for end of life care support, out-of-hours services and after death practicalities
- Sharing of experiences: project presented at local, regional and national conferences, resulting in contact from other municipalities, health care regions and individual professionals. Open web resources and a network forum are under construction.

Conclusion

The interest and raised awareness suggest an unmet need for this competence. Resource staff play an important role in making colleagues more confident and prepared to provide palliative care to people with intellectual disabilities. Together we can manage.

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