Palliative Care is everybody’s business - Self-Directed Learning Package for disability support workers

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Rationale

- Ageing population
- Vulnerability of people with disabilities
- Deinstitutionalisation of disability care
- Higher complexity of health care needs
- Inappropriate management in Emergency Departments
- Difficulties in clarifying most appropriate decision maker
Process

- Palliative Care invited to conduct workshop at Disability SA Conference 2012
- Feedback collated to identify themes
- Agreement to develop self-directed learning package +/- supplementary education
- Reverse PEPA + SAPS funded
Themes

- Clinical Issues
- Psychosocial Issues
- Care Planning/Advance Directives
- Accessing palliative care resources
- Staffing/Role delineation
Aim

- Develop a learning package to enhance the skills and knowledge of Disability SA carers involved in the care of patients with a terminal illness
Objectives

- Greater understanding of recognising the deteriorating client and how to respond
- Better understanding of assessment and symptom management strategies
- Better understanding of communicating with a person who has been given bad news
- Greater understanding of the role of anticipatory directives and their role when clients are deteriorating
- Development of skills to communicate and support family members when a client is deteriorating
- Better understanding of community resources that are available.

SA Health
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- What Needs to be Put in Place?
- End of Life – Palliative Care Decision-Making Process
- What do I Say? – Communicating about Illness and Dying
- Symptom Management
Contents

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- Managing Loss and Grief
- Reference List and Resources
- Answers to Questions
Case Study

Michael was a 42 year old man diagnosed with multiple sclerosis, neurofibromatosis, cognitive impairment, and a closed head injury in 1987. He was living in a shared house in community supported accommodation in Disability Services for about three years. He had been admitted to hospital a number of times over the previous year, and was deteriorating in that he was now unable to verbally communicate, move himself, and required assistance to eat and drink a vitamised diet. The Disability Community Nurse liaised with the accommodation manager and the family to make a referral to the local Palliative Care Service for a review of the situation.
Example

Recognising a Deterioration in a Person’s Health Status

Things to look out for:

- swellings or lumps
- clothes not fitting properly due to changes in body shape
- weight loss or gain
- personality changes
- changes in eating habits
- changes in toilet habits
- generally feeling unwell
- tiredness or lethargy
- changes in behaviour
- frequent choking at mealtimes or on saliva
- asking for or requiring more pain relief than usual.
Q2: If you notice a deterioration, or are concerned about the person’s health status, what would you do?

Q2: As soon as there is a suspicion of any health change the person will need to visit their general practitioner (GP). The GP will make the decision if the person’s health is in decline, if further investigations are required or a palliative approach is appropriate. An immediate review of the health support arrangements for the person will be required if he/she is now to receive palliative care. The accommodation manager will use the Health Support Risk Assessment tool in the Direct Health Support of People with a Disability Guideline to do this.
Progress

- Package completed
- Being reviewed by Specialised Services and Clinical Governance at Disability SA
- Still awaiting approval to pilot and evaluate
Conclusion

- Successful collaboration between Specialist Palliative Care and Disability Services
- Agreement in relation to Personalised Palliative Care Guidelines
- Has lead to exploration of other opportunities ie. community respite options