

Supporting End of Life Choices

Project summary

Due to advances in health care, people with learning disabilities are enjoying greater longevity. The number of adults with learning disabilities aged over 60 is predicted to increase by 36 per cent between 2001 and 2021 (Emerson & Hatton, 2004).

However, with the greater likelihood of reaching older age, comes an increased risk of developing prolonged life limiting conditions.

11.7%-17.5% of people with learning disabilities, living in institutional settings develop cancer. While this is lower than the general population, estimates of prevalence of people living in community settings are closer to those of the general population (Hogg & Tuffrey – Wijne, 2008). In addition people with learning disabilities are more likely to have a delayed diagnosis, reducing the likeliness of positive outcomes (Tuffrey – Wijne, 2002).

14-20% of People with learning disabilities die of Coronary heart disease (Hatton, Elliot & Emerson, 2002), compared to 4-6.5% of people in the general population (heartstats.org).

21% of people with learning disabilities, over the age of 65 will develop dementia, compared to 5.7% of people in the general population. People with Down's Syndrome are at even greater risk, with 54% of over 65's developing Alzheimer's type dementia (Brooks, 2008).

With publication of the End of Life Care Strategy and the broadening of the role of palliative care services to include conditions other than cancer, the provision of quality end of life care services for people with learning disabilities has become increasingly important.

The "Supporting End of Life Choices" project was developed in order to address these issues. It aimed to raise awareness and improve practice relating to End of Life Choices for People with Learning Disabilities within both learning disabilities services and in generic health care services, including specialist palliative care services in Surrey. The project received funding from the LDDF and started in February 2009 for one year.

The project aimed to produce two main outcomes, a think tank day and a set of information resources (for people with learning disabilities, their staff & carers and staff working in end of life care).

Think tank day – 23rd April 2009

The “Think Tank day” event aimed to raise awareness amongst learning disabilities and generic health care staff, provide an opportunity for staff across organisations to share information and network and to produce an action plan in order to inform the project’s future work and outcomes.

The event was divided into two parts. Delegates heard presentations in the first part of the day and were involved in action planning during the second part.

The presentations covered end of life care from both a palliative care and learning disabilities perspective, together with information on organ donation and transplantation.

In order to improve communication between specialist palliative care and learning disabilities services delegates received packs including a map of specialist palliative care services showing their catchment areas, a table of the services provided by each of the specialist palliative care services and information on local learning disabilities services.

52 people attended from 11 different services, including all four hospices in Surrey. Delegates’ stated objectives were to learn more about learning disabilities/ EoLC (33%), share information (29%), improve practice (21%) and network (8%). Delegates felt that these objectives were fulfilled, providing an average score of 4.15 out of 5.

The action planning session produced a number of useful outcomes.

15 projects relevant to end of life care were identified in Surrey. Many of the projects have aimed to improve access to other services, but are relevant to end of life care. Notable examples of projects specific to end of life care include the educational work done at the Bentley day centre and the training courses at the Phyllis Tuckwell and Princess Alice Hospices.

Delegates were able to independently identify many of the barriers faced by people with learning disabilities that have been highlighted in the literature, such as gaining access to mainstream services, disclosure and care coordination and planning (Tuffrey – Wijne, 2003). Through working together with learning disabilities staff in this exercise staff working in end of life care would have become more aware of the issues for people with learning disabilities.

Delegates identified four key areas of special consideration needed for people with learning disabilities; training, communication, continuity of care & partnership working and sharing information. Delegates developed a number of action points in order to support these considerations. These outcomes were circuited amongst delegate after the information was collated.

Three of the identified action points overlapped with the remit of the supporting end of life choices project. The development of accessible information for people with learning disabilities, their staff and carers on end of life care choices, (including information regarding organ donation), the development of a directory of services and the development of training programmes.

Information resources for people with learning disabilities, their staff and carers and staff working in end of life care were developed in order to address these points.

Development of information resources

The need to develop information resources was highlighted during the Think Tank day. Many resources have been developed for staff and carers working with people with learning disabilities and people working in end of life care. Therefore, it was decided that information resources for these groups should briefly cover the main issues, as identified in the literature (Li & Ng, 2008, Ng & Li, 2003, Tuffrey – Wijne, 2003) and should include a resource CD bringing together the numerous useful resources developed elsewhere.

Fewer accessible information resources regarding end of life choices exist for people with learning disabilities. The resource developed within this project for people with learning disabilities comprehensively covers the issues and will serve as an educational and informational resource for people with learning disabilities in Surrey.

A Good Death – A Guide about End of Life Care for Staff and Carers of People with Learning Disabilities in Surrey

This resource uses the steps of the End of Life Care strategy to provide the basic information. Two steps, “making arrangements for the future” and “recognising illness” were added to the beginning of the pathway in order to cover additional material required for working with people with learning disabilities. Resources were trialled with staff groups from three residential care facilities, one of which specialises in caring for people with learning disabilities who have dementia. The resource CD includes a number of original resources including checklists for before and after death, a contacts resource with local information regarding palliative care services and an accessible information leaflet regarding organ donation.

A Good Death – A guide for Staff in Acute and Palliative Care settings on working with People with Learning Disabilities in End of Life Care in Surrey

This resource is designed to give brief information about the nature of learning disabilities and the special communication and assessment skills required to work with this population. The resources were sent, for consultation, to a sample of the stakeholders from the Think Tank day, working in end of life care.

A Good Death – Information about getting older and dying for people with learning disabilities

This resource is designed to be an accessible information booklet for people with learning disabilities, to be used with support from staff and carers. The booklet starts by explaining about getting older, what death is, and what makes people die. There is then information on what happens if you get very ill, and choices that can be made about what happens when you are ill. The next section gives information about the choices that can be made about what happens after you die. The final section looks at what happens when someone else dies. All the information is written in easy to understand language, with pictures to aid understanding.

This booklet is currently being piloted by a community learning disability nurse with 4 people with learning disabilities, and by a manager at a residential home.

Organ Donation- A leaflet for people with learning disabilities

This accessible leaflet aims to explain about becoming an organ donor. It explains what tissues and organs are, and what happens when a person dies. It tells the person about why organ donors are needed, and what will happen if someone chooses to become an organ donor, with details of how to register.

This leaflet is being offered to the National Organ Transplant service for possible adoption by them.

Think Tank Follow-up Meeting- 14th December 2009

A follow-up meeting was held in December to feedback about the work that has been done for this project. Everyone who attended the Think Tank Day in April was invited to the follow-up, and 10 people from a range of service types attended.

Attendees viewed and commented on the resource booklets, suggesting changes, which were subsequently made to the booklets. A discussion was also

held over any issues and good or poor practice that people had come across in the time between meetings.

Sustainability

- The Think Tank day report, including the collated action points, was distributed to the stakeholders. The project has been presented to the Surrey Learning Disabilities Partnership Board in February 2010.
- The booklets have been presented to the SWSH Network Supportive and Palliative Care meeting in February 2010.
- The project has been presented to the Surrey and Borders Partnership NHS Foundation Trust Learning Disabilities Quality Action group in January 2010.

The resources will be available online through the Learning Disabilities Partnership Board's website (www.surreypb.org.uk) and the Health Action website (www.surreyhealthaction.org) Hard copies will also be printed and distributed to Learning Disability services and Carers, Acute and Palliative Care services, and People with Learning Disabilities.

Recommendations

1. People with learning disabilities should be offered the opportunity to plan for their End of Life via their person centred plan, using the booklet as a guide.
2. An audit should be carried out in one year to evaluate the use of the End of Life booklet and how this has assisted in the development of end of life plans.
3. Booklets for staff, carers and people with learning disabilities will be disseminated widely across Surrey – this could include a presentation at the Providers Forum
4. Continued work is needed to make and maintain links between Palliative Care and Learning Disabilities services to ensure that people with learning disabilities receive excellent end of life care.

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