



Adapting end of life care materials

Gateshead and South Tyneside Sight Service

Sight Service tested how end of life care workforce materials could be used to improve care delivery for people with sensory difficulties.





Background

Skills for Care developed end of life care workforce materials. Test sites were recruited to provide feedback about how these could be used to support workforce developments and improve end of life care delivery for people with additional needs, such as sensory impairments. Projects also looked at the implications for other groups of people, including those with mental health problems, learning disabilities and specific faith groups.

Sight Service was successful as a test site and engaged with service users and representatives from Action on Hearing.

Aims and objectives

The aims of the project were to evaluate the impact:

- on workforce development in support of the end of life care strategy during 2010-2011
- of varying approaches to regional dissemination of the materials.

The objectives for the test sites were to:

- test the materials with specific care groups and a range of staff, carers and volunteers
- reflect on how well the material met the needs of the specific workforce
- describe issues for the service users and workforce
- suggest revisions to the material for the specific situation
- produce additional material that other employers could use
- participate in dissemination of the findings.

What was done?

The materials were shared with local stakeholders and organisations who worked with people with visual and hearing impairment. The range of challenges that are associated with delivering end of life care to people with visual and hearing impairments was identified. These were linked to the four key competences identified as part of the workforce initiatives: assessment, advance care planning, communication and symptom management. Stakeholders agreed that these areas were important, but that the materials would need amendment to be applicable to people with sensory impairment.

There was also consultation with service users and carers about their experiences of end of life care delivery, particularly with reference to the assessment process, communication, information or advance care planning.



Findings

It is important that everyone approaching the end of life:

- is treated with dignity and respect
- gets clear information about their condition
- is communicated with effectively
- is fully included in all treatment and care provided.

These criteria can be difficult to meet when people have sensory impairments. BID Services (2009) identified that the lack of integration between services and the barriers to communication mean that many deaf people are denied the support they need. They often lack a full understanding of what is happening to them, resulting in isolation, confusion and unnecessary fear.

Giving written information to people with sight loss requires particular attention; leaflets may be in small print and some people may need resources in braille. It is good practice to contact people to arrange visits and allow them an opportunity to check with their GP or hospital if they cannot read the visitor's identification. Basic etiquette around communication when speaking to someone with sight problems includes:

- speak in a natural conversational tone, it is not necessary to speak loudly
- address individuals by name, especially when others are present
- speak directly to the person, not through someone else
- greet the individual as you enter so they know you are present
- indicate the end of a conversation before speaking to someone else.

Outcomes

Sight Service developed a range of case studies highlighting important considerations when delivering end of life care when people or family members have impaired vision or hearing difficulty. The case studies guided staff on best practice principles to deliver effective care.

The case studies were:

- shared with a range of service user groups and feedback was positive
- presented at health and social care partnership boards
- circulated to a range of health and social care professionals in the locality.

Emphasis was placed on how to ensure achievement of the workforce competencies, eg improving achievement of preferred place of care, especially in instances where people wish to be cared for at home, but require major equipment to be installed, or housing adaptations to be made in order to facilitate this.



Information was given about the role of Sight Service and Action on Hearing in providing additional support and holistic assessment. Individuals were also informed about training and referral systems to other services, such as occupational therapy, rehabilitation or specialist palliative care.

The feedback from these projects was incorporated into a workforce development guide (Skills for Care, 2012).

Next steps

Since completing the project, the case studies have been updated and shared with local clinical commissioning groups to identify specific needs. Sight Service has been invited to be on the board of the local clinical commissioning group.

References

Bid Services, 2009 A Guide to Working with Deafness and Palliative Care. Best Practice Booklet, Bid Services, 2009. http://bid.org.uk/uploads/Pall_Care_Guide.pdf

Skills for Care and Skills for Health, 2012

Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care, Skills for Care and Skills for Health, 2012. http://www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx

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Further information

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