A fast track path improves access to palliative care for people with learning disabilities

People with learning disabilities are now living longer and may develop diseases such as cancer. A fast track referral pathway ensures their needs are met by the medical consultant and the director of patient services from the hospice.

The group identified a need to create a fast track referral pathway for people with learning disabilities and a life limiting illness. This would mean early face to face contact and the opportunity to build positive relationships, which might, in turn, prevent the need for crisis management.

The referral pathway
The hospice referral form has been adapted to highlight whether patients have a learning disability. A specific code featuring their vulnerability is entered onto the electronic patient record system. Those with a learning disability are highlighted at the hospice’s referral meeting.

Within one day of receiving the referral, the triage team makes telephone contact to obtain key information on the patient, which is gathered from someone who knows them well, such as a key worker, relative or community learning disability nurse.

The pathway has prompts for the triage nurse to request health information in any of the formats the person may use, such as personal health records, health passports or hospital communication books. There is also a prompt to check whether the person is known to the local CLDT and to refer and liaise with them if necessary.

Patients with learning disabilities are prioritised for an early home visit, which is undertaken with someone who knows them well. The aim is to understand as much about the patient as possible, allowing for a person-centred approach.

Multiprofessional team working
If the referral is appropriate, the case is presented at the multidisciplinary team meeting, with an open invitation for key workers to attend if they so wish. Specific needs are discussed to ensure there is an understanding of the patient and their support network.

The hospice clinical nurse specialists work jointly with someone who knows the person...
well to plan care and identify any specific needs for palliative care staff. Risk assessments are essential to care planning.

**Future planning**

Our clinical experience and discussions with clients and carers show that many people with learning disabilities prefer to receive care at home rather than as hospice inpatients. In addition, they are also more comfortable in their own surroundings. This means that staff need to consider the care setting carefully.

Future bereavement needs are also considered, including pre-bereavement work and provision of specific learning disability literature for family and friends, some of whom may also have learning disabilities.

**RESOURCE PACKS**

The networking meetings also highlighted that the hospice needed more information on learning disabilities. Resource packs were developed for each clinical area, with relevant information such as contact details for the CLDTs and useful tips on caring for people with learning disabilities.

**CHAMPIONS IN LEARNING DISABILITY**

Another idea was to identify champions, that is, specialist palliative care staff with an interest in learning disabilities. Two people were identified to act as a link to the CLDTs, which has worked well. The champions act as a point of contact to discuss individual cases, provide support, as well as promoting the joint work to hospice staff.

**CONFERENCE**

The hospice held a conference focusing on learning disability and end of life care in November 2008. A range of speakers who have published widely on the subject gave presentations, including Irene Tuffrey-Wijne (author of the Research Report on page 15). Three carers shared stories about their relatives who had learning disabilities and life limiting illnesses, which highlighted both positive and negative experiences from which we could learn. Service development needs and a plan for the way forward were drawn together and the pathway was officially launched.

**OUTCOMES**

As a result of the referral pathway, the hospice now has a way of capturing information about the number of people with learning disabilities who are receiving end of life care. This information has been audited and, in the last year, seven people with learning disabilities and advanced illness have been seen at the hospice. The audit has demonstrated that staff making referrals have welcomed the early initial contact and an opportunity to discuss problems and plan together.

However, the work has highlighted a need for awareness training on the health needs of people with learning disabilities for both primary and acute care staff. This training should also include the complex issue of palliative care needs.

**SHARING PRACTICE**

We are promoting the pathway through the work of the National Network for Palliative Care of People with Learning Disabilities. The medical director and director of patient services from the hospice had a poster displayed at the 11th Congress of the European Association for Palliative Care in Vienna in May 2009 on the project.

**CONCLUSION**

Collaborative working is essential to ensure people with learning disabilities receive good quality palliative care. By sharing knowledge and expertise between learning disability and palliative care staff, we have realised that neither group has all the answers. Learning disability nurses have shared the latest documentation and accessible health information and palliative care staff have shared documentation and tools. Through collaboration, the group has learnt about each others’ roles and responsibilities.

This work has been proactive and refreshing as the local hospice took the initiative and approached learning disability services to work with them rather than the other way round, which is so often the case. We believe this work and the pathway could be transferred to other hospices and CLDTs throughout the country to improve access more widely.

The referral pathway will hopefully ensure that people with learning disabilities have a coordinated and seamless journey in the last stages of their life.

For further information on this project, please contact Jane Whittington at jane.whittington@havering.gov.uk.

**REFERENCES**


