

An Ordinary Death?

**The service needs of people with
learning disabilities who are dying**

SUMMARY

This qualitative project explored the issues facing residential services who provide care for someone with a learning disability who is dying. The work was funded as part of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities. It focused primarily on the needs of older people, looking particularly at where the person died and whether they were told openly of their diagnosis, in order to explore how far the service had been able to make an ordinary death possible. The study found that people with learning disabilities, who suffered an illness, were often diagnosed late, as a result of which they did not have access to standard curative treatments and that even serious clinical decisions were sometimes made without following usual procedures. The study recommends an annual audit to ensure that people with learning disabilities, who suffer a terminal illness, receive palliative care that is properly informed by 'normal' good practice especially in regard to symptom control, pain relief and access to mainstream hospice services.

BACKGROUND

The project findings suggest that people with learning disabilities present late with serious illnesses and do not have access to the usual standards of preventative or curative health care. When being treated on regular hospital wards their care can also fall below that offered to others in quite ordinary ways. This can include leaving someone to eat on their own when they cannot manage this, or having symptoms ignored as if these were an integral part of their impairment when in fact they signal important changes in their condition. Such experiences deterred some residential care services from seeking input to palliative care from hospitals, hospices or from home nursing teams (see WHO, 2001; UN, 1994). There has been little previous work on these issues so it was thought important that the GOLD project explored how death and dying were being managed in residential settings, as these findings would have an enormous impact on older people with learning disabilities and their co-residents, partners and friends.

THE RESEARCH

The project was based on a series of case studies exploring the way 12 residential services had responded to the needs of 21 people with learning disabilities who had died primarily as a result of illness. In all, 31 interviews or meetings were conducted with care staff, 16 with service managers, 18 with health care/learning disability professionals, three with service users, six with family members, eight with local community representatives and five with staff/community teams. The researchers also sought the views of the user group attached to the GOLD project. The study was qualitative and exploratory and the researchers are very grateful for the contribution made by these individuals, services and networks.

THE FINDINGS

The following features were used by staff to describe a well-managed death:

- Diagnosis is prompt and followed up by curative treatment for as long as this is practicable and feasible.
- Treatment decisions were made on the basis of evidence, the patient's informed choices and/or their best interests.
- The transition from curative to palliative treatment and nursing is then managed appropriately so that intrusive interventions are not still being tried when the person is approaching death, adding to physical burdens of pain or tiredness.
- The death takes place at home or in a setting which is as homely as possible and where the person's previous social bonds can be maintained and acknowledged right up until the time of, and after, the death.
- Physical symptoms are well managed and pain is avoided: there is no inappropriate prolonging of life or resuscitation when death is inevitable.
- Psychological symptoms are well managed and unnecessary distress is avoided usually by disclosing the prognosis and helping the person to prepare themselves, so that the person is not left isolated.
- Death is 'timely': there is a sense that it is the right time for the person to die and there is some degree of readiness as each stage gives way to the next.
- Relatives, carers and other loved ones are helped to prepare for the person's death and supported afterwards.
- Different professionals and different agencies working together seamlessly.

But many of these deaths fell short of these ideals, particularly in relation to diagnosis and treatment, openness and access to mainstream healthcare and palliative care services.

Most staff did not find this aspect of their work as stressful as they expected and several teams commented positively on the degree of cohesion their shared commitment had generated.

The study demonstrated a lack of a coherent decision-making process in relation to treatment and care. Decision-making issues are most acute when the treatment goal shifts from curative to palliative. When most people develop a life threatening illness they want the best interventions while preserving their right to refuse curative treatment at the end of their lives. This is not what happens for people with learning disabilities where standard diagnostic tests or standard clinical pathways were not always followed. Some of these decisions received neither informal nor formal scrutiny although the research also documented some examples of very good multi-disciplinary decision-making in relation to such interventions as blood testing and PEG tube feeding.

IMPLICATIONS

- Community teams should monitor deaths in their catchment area and review inter-agency arrangements, including the involvement of specialist palliative care and dementia services.
- To avoid late presentation of serious illness, services should ensure that people with learning disabilities participate in all available screening programmes and that proper diagnostic tests are carried out wherever unexplained symptoms or physical changes are noted.
- Significant decisions, for example to depart from normal clinical pathways, should be made in a formal case conference with recourse to independent advocacy or mental incapacity guidelines.
- Clinicians should do all they can to inform workers in the residential setting, and other carers, of the likely trajectory of the illness so that carers can gauge their input over time and make the necessary material and emotional adjustments.
- People with learning disabilities should be helped to die at home unless their needs are too complex or their dying too protracted for this to be managed. The criteria for entry into specialist services should be the same as those for people who don't have learning disabilities, including equitable access to mainstream hospice services.
- Pain relieving medication or sedation should be prescribed according to the clinician's normal expectations of the needs of other patients with similar illnesses. The physician should not wait to be asked.
- Those closest to the dying person should be able to decide when and if the person's questions should be answered openly.
- Care managers must be authorised to vary resources to allow a person to stay in their current placement during a final illness. NHS Trusts should negotiate and establish standard protocols (proactively not reactively) to govern who should pay for staff to augment care when people are being treated in hospital or when significant health care is being provided in a social care setting.
- Commissioners and partnership boards in England should ensure that palliative care needs are featured in local plans and joint investment plans.

The project, conducted over the period of 1999–2002, was timely in that it coincided with decisive national and international acknowledgement of the poor health status of people with learning disabilities. Facilitating access to health care, (and this must include palliative care), on behalf of people with learning disabilities is at the heart of the recent English White Paper, *Valuing People*. The study may also inform proposed new mental incapacity legislation, which is being drawn up on the basis of international human rights agreements.

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Further details of the study may be found in:

Brown, H. Burns, S. and Flynn, M. (2002) *Supporting people through terminal illness and death in Today and Tomorrow: The Report of the Growing Older with Learning Disabilities Programme* London: The Foundation for People with Learning Disabilities

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