

“There is a need for patients with a learning disability to be given access to the same services providing specialist palliative care as other individuals.”

Many people with a learning disability find it hard to access end-of-life care and support.

The 12 messages in this booklet have been developed from conversations with people with a learning disability, families and carers, advocates, health and social care clinicians.

This A6 guide is a summary of the main points made in ‘Living and dying with dignity: the best practice guide to end-of-life care and support for people with a learning disability’.

The guide has been produced by Mencap’s North Staffordshire Palliative Care Project, following a two-year collaboration with Keele University, and with support from the Big Lottery Fund.

To order a copy of the guide or the easy read summary, call **01159 827 022** or download them at **www.mencap.org.uk/endoflifecare**

Registered charity number 222377 2007.354_03/09



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Living and dying with dignity:

the 12 main messages

Ensuring all people with a learning disability receive inclusive end-of-life care services.





- 1.** People with a learning disability often experience barriers to end-of-life care and support. Professionals should be aware of these barriers and try to overcome them.
- 2.** Carers should talk openly and honestly about all aspects of death and dying while the people they support are well and healthy.
- 3.** Communication is the key to effective end-of-life care and support.
- 4.** Carers should encourage the people they support to look for changes in their bodies and help them to be aware of the importance of health and wellbeing clinics, classes or groups.
- 5.** Carers should ensure they identify any changes in the health status of the person they support, seeking professional advice where appropriate.
- 6.** Talking to family and friends, and working with familiar carers, provides a clearer picture of the person and promotes holistic care.
- 7.** Preparing the patient for diagnostic procedures and tests is very important. It takes time, creativity and forward planning.
- 8.** Breaking difficult news should be done by familiar carers – they must be guided by the person receiving the news and carers should avoid creating unrealistic expectations.
- 9.** All people involved in a person’s life will need variable support both when the person dies and afterwards.
- 10.** People with a learning disability must be treated with respect and dignity, and treated as an adult throughout their illness.
- 11.** End-of-life care and support is delivered by many different people. Professionals must ensure they work together effectively.
- 12.** Every person involved in end-of-life care must always do their very best to give every person with a learning disability the support they deserve and need.