



**The voice of
learning disability**



**Delivering the right support for people
with a learning disability**



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**Cruse bereavement care conference
2008**



History of Mencap and learning disability



- 1900's - large institutions to 'protect society'
- 1946 - Mencap established
 - Education was the goal
- 1980's - community care and hospital closures

Mencap and learning disability



- Village communities
- 2001 Valuing People
- 2008 APPG on Human Rights of people with a learning disability



Dying and loss



- Disraeli, 1881
 - Queen Victoria having proposed to visit him –
“Why should I see her? She will only want me to give a message to Albert”



- Palmerston, 1865
 - “Die my dear Doctor? That’s the last thing I shall do!”



Stages of mourning



- Denial

- Pain

- Adjustment

- Moving on





Assumptions

- Not able to cope with loss
- Excluded from rituals and processes
- Not able to cope with funeral







The right support



- Mental Capacity Act
- Communication
- What happens when you lose someone?
- Inclusion is vital!



The right support (cont)

- 30,000 living with elderly parents
 - Loss of parents => loss of home
 - Hidden losses
 - Vital that pictures, mementos, stories are not lost
- Accessible information
- Conversations to remember loved ones
- Those without speech
- Anne Craft Trust





New developments



- Bereavement needs assessment tool
 - Clarify the specific bereavement needs
 - 10 questions
 - 3 areas
 - Practical issues
 - Social issues
 - Emotional issues

Model for assessing grief responses for an individual with a learning disability

(1st draft of assessment tool, Noelle Blackman, British Journal of Learning Disabilities, 36, 165 – 170)



- Emotional responses
- Cognitive understanding
- Social responses
- Social impact
- Physical
- Lifestyle



Conclusions

See the person – not the disability





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