

Core questions every year

2000-2007 (n=23588)

**General demographics##**  
(of the respondent)  
- age, gender, country of birth, marital status, highest level of education, rural/metropolitan residence, current work status #;  
(of the household)  
– annual gross income

**Questions specific to end-of-life issues**  
‘In the past five years, has anyone close to you died of a terminal illness...?’ Causes of death on a flash card included cancer, motor neurone disease, multiple sclerosis, emphysema / other lung disease, end-stage heart failure, end-stage liver failure, end-stage kidney failure, HIV/AIDS, other, don’t know; Did the person who died of a terminal illness use a palliative care service?\*

Additional end-of-life / palliative care questions asked

**2001-2007 (n=20561)**  
Most involved level of care; (“day-to-day hands-on care” (care 5–7 days per week); “intermittent hands-on care” (care 2–4 days per week); or, “rare hands-on care” (care 1 or less days per week)),  
Time since death;  
Relationship to the deceased;  
Expectations between diagnosis and death;  
Ability to ‘move on’ with life;  
Why a palliative care service was not used

**2002-3, 2005-7 (n=14539) (on flash card)**  
**Domains where additional support would have been useful for you or the person who died?**  
**Physical care; medications; symptom control; information about illness progression, services. Emotional support for respondent, deceased; spiritual, financial or bereavement support; other support; no additional support needed.**

**2003-7 (n=14509)**  
Length of time care for which care was provided

**2004-6 (n=3051)**  
Level of comfort in the last two weeks of life

**2004-6 (n=9001)**  
Place of death;  
Use of bereavement services;  
Age of the person who died

**2006-7 (n=5476)**  
Would you take on the caregiving role again?

\* Gateway question to the section on end-of-life / palliative care. If the answer was ‘no’ the respondent moved onto the next section of the survey.  
\*\* Always asked at the end of the questions to ensure that palliative care issues were not pre-empted  
# not asked in 2006 (n=2969)  
## researchers have no influence over these questions