

CI Identifier:..... (Office use only)



Confidential Inquiry Team

Norah Fry Research Centre

3 Priory Road
Bristol, BS8 1TX

Tel: 0117 331 0980

Fax: 0117 331 0978

Email: ci-team@bristol.ac.uk

Web: www.bris.ac.uk/cipold/

Confidential Inquiry into Deaths of People with Learning Disabilities

Form B2

Death of a person with learning disabilities who had a life-limiting condition including but not limited to palliative care services

Main diagnosis / diagnoses:

Life-limiting /life-shortening conditions are those for which there is no reasonable hope of cure and from which the person will die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on carers.

These conditions fall into 4 main categories (www.act.org.uk); please tick the category that most closely fits this person's condition:

☐ **Life-threatening conditions for which curative treatment may be feasible but can fail.**

Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failure of heart, liver, kidney.

☐ **Conditions where premature death is inevitable**

Where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

☐ **Progressive conditions without curative treatment options**

Where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.

☐ **Irreversible but non-progressive conditions causing severe disability**

leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

☐ **Other. Please specify:**

☐ **Not known**

CI Identifier:..... (Office use only)

Was there an end-of-life / advance care plan in place for the person?	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
Was there a preference for location of end-of-life care? If so, where:	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
<input type="checkbox"/> Home	
<input type="checkbox"/> Hospital	
<input type="checkbox"/> Hospice	
<input type="checkbox"/> Other. Please specify:	
Did the person die in the preferred location? If not, why not:	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
Was there a 'do not attempt resuscitation' / 'Allow Natural Death' request in place?	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
Was there a referral for or input from hospice team before death?	Y <input type="checkbox"/> N <input type="checkbox"/> Service not available <input type="checkbox"/> Not known <input type="checkbox"/> Date of referral / /
Was there a referral for or input from home based specialist palliative care support?	Y <input type="checkbox"/> N <input type="checkbox"/> Service not available <input type="checkbox"/> Not known <input type="checkbox"/> Date of referral / /
Was there a recognised terminal phase and/or final illness episode?	
If so, how long did this last?	
What was its nature? (e.g. chest infection, exacerbation of seizure activity, gradual decline in progressive condition)	

CI Identifier:..... (Office use only)

Please describe the manner of death

Was the death due to (circle or tick all that apply):

- | | |
|---|---|
| a) Natural progression of underlying condition | Y <input type="checkbox"/> N <input type="checkbox"/> |
| b) Recognised complication of condition | Y <input type="checkbox"/> N <input type="checkbox"/> |
| c) Recognised complication of treatment | Y <input type="checkbox"/> N <input type="checkbox"/> |
| d) Acute event or illness related to the underlying condition | Y <input type="checkbox"/> N <input type="checkbox"/> |
| e) Acute event or illness unrelated to the underlying condition | Y <input type="checkbox"/> N <input type="checkbox"/> |
| f) External cause | Y <input type="checkbox"/> N <input type="checkbox"/> |
| g) Other (specify) | |

Not known	Y <input type="checkbox"/> N <input type="checkbox"/>
-----------	---

Who is providing bereavement support to the family/carers

- ☐ Community
- ☐ Hospice
- ☐ Hospital
- ☐ Bereavement charity
- ☐ Combination
- ☐ Other. Please specify:
- ☐ Not yet known

Is specialist bereavement support available locally if needed?

- | | |
|---------------------------|---|
| a) For family / carers | Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/> |
| b) For significant others | Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/> |

CI Identifier:..... (Office use only)

Comments regarding care at the end of life and around the time of death and bereavement: e.g. what went well, what could be improved, were there any difficulties in obtaining or coordinating services?

	Issues	Suggestions, learning or action points for the future
Agencies or teams involved in care		
Issues encountered in the person (eg symptom control, emotional well-being, communications, practical issues with care)		
Issues encountered with the family (e.g. psychological support, communications, finance, equipment, housing, respite)		
Issues encountered with service providers (e.g. co-ordination, communications, funding, accountability)		
Issues encountered at or after death (e.g. practical issues around informing and coordinating services, notification of death, Certification, transfer of person's body)		

Thank you for completing this form. Please return it as soon as possible to the CI team.

You can return the form:

- by post: CI team, Norah Fry Research Centre, FREEPOST (SWB 1630), Bristol BS8 1ZZ
- by fax: 0117 3310978

Thank you.