



Form B3 – Death of a child with known life-limiting condition

MSCB Reference

CD11/12 xxxx

Form B3 – Death of a child with known life-limiting condition including but not limited to palliative care services.

Form B3 is to be completed by the lead clinician or designated member of the palliative care team

Main diagnosis / diagnoses:

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

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

Was there an end-of-life / advance care plan in place for the child?	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? <input type="checkbox"/>	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
If so, where:	
<input type="checkbox"/> Home	
<input type="checkbox"/> Hospital	
<input type="checkbox"/> Hospice	
<input type="checkbox"/> Other. Please specify:	
Did the child die in the preferred location?	Y <input type="checkbox"/> N <input type="checkbox"/> Don't Know <input type="checkbox"/>
If not, why not:	
Was there a 'do not attempt resuscitation' / 'Allow Natural Death' request in place? Know <input type="checkbox"/>	Y <input type="checkbox"/> N <input type="checkbox"/> Don't <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)	
Please describe the manner of death	

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

a) Natural progression of underlying condition Y N

b) Recognised complication of condition Y N

c) Recognised complication of treatment Y N

d) Acute event or illness related to the underlying condition Y N

e) Acute event or illness unrelated to the underlying condition Y N

f) External cause Y N

g) Other (specify)

Not known Y
N

Who is providing bereavement support to the family

Community

Hospice

Hospital

Bereavement charity

Combination

Other. Please specify:

Not yet known

Is specialist bereavement support available locally if needed?

a) For parent(s) Y N Don't Know

b) For sibling(s) Y N Don't Know

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 child (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 child's body)		