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Make provision for NHS service commissioners to ensure that persons for whom they have responsibility for commissioning physical and mental health services have access to specialist and generalist palliative care and support services; and to make provision for treatment of children with a life-limiting illness.

BE IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

1 Palliative care and support

- (1) In exercising functions in relation to the health service in England, the Secretary of State must ensure that contractors of clinical services provide, to such extent as necessary to meet reasonable requirements, for—
- (a) access to specialist palliative care in hospital, in the community and in places of usual residence; 5
 - (b) facilities for the care of patients with life-limiting and life-ending conditions;
 - (c) general and specialist palliative care services consistent with the Duty as to reducing inequalities specified in section 4 of the Health and Social Care Act 2012. 10
- (2) Where any hospice service in England is commissioned from a voluntary sector provider, patients eligible for NHS treatment and medication must receive pharmaceutical services through NHS pharmacy provision.
- (3) An NHS clinical services commissioner, in exercising functions under section 3(1)(c) of the National Health Service Act 2006, must ensure that—
- (a) persons in their area with palliative care needs have access to appropriate health services, including, but not limited to, access to specialist palliative care; and 15
 - (b) clinicians providing general palliative care have access to specialist palliative care advice at all times. 20

- (4) NHS clinical services commissioners must include the provision of specialist palliative care and hospice care in any strategic plans to meet the needs of adults and children predicted to require such services.

2 Treatment of children with a life-limiting illness

- (1) This section applies where there is a difference of opinion between a parent of a child with a life-limiting illness and a doctor responsible for the child's treatment regarding –
- (a) the nature or extent of specialist palliative care that should be made available for the child, or
 - (b) the extent to which palliative care provided to the child should be accompanied by one or more disease-modifying treatments.
- (2) The hospital board must, upon being informed of a difference of opinion under subsection (1), take all reasonable steps –
- (a) to ensure that the views of the parent are taken into account in deciding the questions in subsection (1);
 - (b) to make available to the parent any medical data relating to the child reasonably required to assess the parent's proposals for the child's treatment (including obtaining an additional medical opinion);
 - (c) to refer the difference of opinion to the appropriate clinical ethics committee of the hospital for advice; and
 - (d) to provide and pay for a mediation process, acceptable to both parties, between the parent and the doctor.
- (3) For the purposes of subsection (2) the hospital board –
- (a) must involve the child's specialist palliative care team as far as possible; and
 - (b) may refuse to make medical data available if the High Court grants an application to that effect on the grounds that disclosure might put the child's safety at risk having regard to special circumstances.
- (4) Notwithstanding any other Act or regulation, where the difference of opinion between the parent and the doctor arises in proceedings before a court, the court may not make any order that would prevent or obstruct the parent from pursuing proposals for obtaining disease-modifying treatment for the child (whether in the United Kingdom or elsewhere) unless the court is satisfied that the proposals –
- (a) would involve a medical institution that is not generally regarded within the medical community as a responsible and reliable institution, or
 - (b) pose a disproportionate risk to the child of significant harm.
- (5) Where the difference of opinion between the parent and the doctor arises in proceedings before a court, the court may not make an order against the parent to impose costs for the proceedings or the costs of any other matter related to the proceedings.
- (6) Nothing in subsection (4) requires, or may be relied upon to require, the provision of any specific treatment by a doctor or institution.
- (7) This section does not apply in relation to court proceedings instituted before it comes into force.

3 Interpretation

In this Act –

- “child” means a person under the age of 18;
- “health services” has the same meaning as in the National Health Service Act 2006; 5
- “health service hospital” has the meaning given by section 275 (interpretation) of the National Health Service Act 2006;
- “NHS clinical services commissioner” includes the NHS Commissioning Board and clinical commissioning groups as defined in sections 1H and 1I of the National Health Service Act 2006; 10
- “palliative care” means care which is delivered to seek to improve the quality of life of persons with life-limiting illness or approaching the end of life, through the prevention and relief of suffering by means of early identification, assessment, treatment and management of pain and other problems whether physical, psychological, social or spiritual; 15
- “parent” means a person with parental responsibility for a child in accordance with the Children Act 1989;
- “places of usual residence” includes places where persons in need of palliative care may be confined and includes care homes, supported residential accommodation, secure mental health facilities and prisons; 20
- “specialist palliative care” means care provided by multi-disciplinary teams of specialists in palliative medicine and palliative nursing and allied health professionals who have undergone specialist training in palliative care, and related supportive disciplines.

4 Extent, commencement and short title 25

- (1) This Act extends to England and Wales.
- (2) This Act comes into force on the day on which it is passed.
- (3) This Act may be cited as the Access to Palliative Care and Treatment of Children Act 2019.

Access to Palliative Care and Treatment of Children Bill [HL]

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Baroness Finlay of Llandaff

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