Deprivation of Liberty
Safeguarding in hospice care: from law into practice

Hot Topics Study Day May 2016
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Aims of today:

• To review Deprivation of Liberty Safeguards legislation: What is it? What does it involve?

• To share experience of current use of DoLS
  - in hospices
  - in hospitals
  - in nursing homes
  - at home

• To share controversies

• And .. work to do?
DoLS timeline

- **July 1997**: ‘H’ is admitted to a NHS mental health ward informally. He lacks capacity to consent to admission but is compliant. He is subject to a number of restrictions whilst on the ward including when he can leave: the ‘Bournewood case’.

- **End of 1997**: High Court rejects an appeal made on H’s behalf that he was unlawfully deprived of his liberty.

- **1998**: The court of appeal overturns the High Court ruling

- **2004**: The European Court of Human Rights rules on the Bournewood case. The UK Government has to respond by creating a legal mechanism to authorise such deprivation of liberty in care settings.
DoLS timeline

- **Oct 2007**: The Mental Capacity Act 2005 comes into force. Expanded to include law/a separate Code of Practice relating to Deprivation of Liberty Safeguards DoLS.

- **Apr 2009**: DoLS incorporated into the MCA 2005. This to ensure that people whose liberty is being deprived so they receive care and treatment and who can’t consent to that care/treatment are protected from being held unlawfully or without appropriate safeguards.
DoLS timeline

- **Mar 2014**: Supreme court ruling – the Cheshire West ruling finds the restrictions that 3 people with Learning Disability are subjected to whilst receiving care / to enable the care they need (high levels of supervision, continuous accompaniment, restriction) mean that they are all deprived of their liberty. This sets a lower threshold for what restrictions lead to a deprivation of liberty.

Deprivation of Liberty Safeguards legislation

- ... the safeguards which protect individuals who are detained in a care home or hospital for the purpose of giving them care and treatment, but who lack the capacity to consent to that treatment or detention.

- The detention, or deprivation of liberty must be demonstrably appropriate, fair, and necessary.

- **March 2014**: the Supreme Court clarified that an individual without capacity is deprived of their liberty in circumstances where they are under the 'continuous supervision and control [of their carers] and are not free to leave.'
  
  The ‘acid test’
What should make a care team consider if they are depriving someone of their liberty?

- The person under treatment or care lacks capacity to consent to that care/treatment
- They are not free to leave (regardless of whether they can physically leave)
  [i.e that care/treatment is deemed essential]
- They are under continuous supervision and control

.... the ‘acid test’
How is that decision reviewed/ratified and safeguards decided?

- The care team (the ‘Managing Authority’) make an urgent application for a DoLS.
- An intense assessment framework is completed by 2 independent assessors from the local authority (the ‘Supervisory Body’).
- Involves speaking with patient, speaking with family and a detailed assessment of care and treatment arrangements.
- If Deprivation of Liberty is authorised a relevant persons representative is appointed. This is family in most cases. They must facilitate appeal to the Court of Protection if the person objects to DOLS.
(How) does DoLS work for the benefit of/ protection of palliative care patients?

“Confusion and uncertainty about when a DoLS application should be made is causing avoidable distress to people at the end of life, their families and carers”

(Caroline May, ehospice, and Karen Lynch, Policy Implementation Manager, Hospice UK 20 March 2015)

• Everyone loses capacity at some stage towards the end of their life: some palliative patients require constant supervision and restrictive practices for their protection
  e.g. patients with dementia: mobile but lacking capacity
  e.g. patients with terminal restlessness requiring sedatives
DoLS and hospices:

• ‘The application of the Supreme Court ruling to patients being cared for by hospices is unclear(*)’.

• Scenarios to trigger discussion:
  • An actively dying in-patient who has lost capacity or consciousness, and is receiving sedative medication to manage symptoms of their terminal phase.
  • A delirious in-patient whose condition and capacity is fluctuating and who is receiving medication or support to manage their state, and hourly intentional rounding.
  • A wandering cognitively impaired in-patient at risk of falls who has a nurse call system that activates when the patient starts wandering.
  • A patient with dementia requiring inpatient care who is prevented from leaving the hospice to ensure ongoing care.

*Hospice UK Nov 2014
For hospices:

- 'An actively dying in-patient who has lost capacity or consciousness, and is receiving sedative medication to manage symptoms of their terminal phase'.

- On a strict application of the MCA 2005:
  - when an individual is unconscious there is arguably an impairment or disturbance of the functioning of the mind or brain
  - The patient is unconscious and they are unable to communicate a decision about where they want to live and receive care.
  - It is likely that the care they are receiving and the environment they are receiving it in, is overwhelmingly in their best interests, necessary and proportionate and as such, meets the key requirements for a DoL needing authorisation.
For hospices:

• **Does an advance decision count for anything?**

• It has been suggested that if a patient goes into a hospice by choice (which is usually the case), they could sign a form to confirm that they give their consent and this might somehow avoid the later implication of a DOLS authorisation once capacity has been lost.

• Legal concern: capacity is time and decision specific. How relevant was that decision then now that things have moved on?
What are hospices doing?

- A wide range of practices
- Range from no applications to multiple applications
Some local experience

SFH Apr 15 – Mar 16

- 374 admissions
- 4 applications
- 3 achieved standard authorisation
- (1 recovered in < 48 hrs)
- 1 discharged home and died
- 1 discharged home, still alive
- 1 discharged to NH and died there (under DoLS)
- Pt with delirium wanting to leave – physically too poorly to but definitely wanting to!
- Pt with dementia always having wanted to be at home – but family just couldn’t cope
- Pt with LD and now advanced cancer. Wanted to be home – trying to get there – but family not able – high care needs
- Pt confused (brain tumour) heads out to pub with oncoming traffic

Work to minimise deprivation of freedom: specialling patients, big room, 1:1 nursing, garden time
Some local experience

St Christopher’s Apr 15 – Mar 16

- 800 admissions
- 8 applications
- 4 assessed
- 3 achieved standard authorisation (1 died)
- 3 died or were discharged before assessment (1 lost)
Some local experience

Peace Apr 15 – Mar 16

- 250 admissions
- 9 applications
- None achieved standard authorisation
- 6 died or were discharged before assessment
- 1 nearly assessed but when LA rang to arrange assessment decided to wait as pt v poorly

- Pt being admitted to the hospice when they did not have capacity, had not consented to being here and were not imminently dying
- Pts losing capacity, and not imminently dying.

**Work to minimise deprivation of freedom:**
- specialing patients, 1:1 nursing, using low beds, bed rails
Some local experience

• **Hospice X:**
  
  “... The safeguarding people were very risk adverse and seemed to think that anyone who became sleepy / drowsy / unconscious had lost capacity and therefore was being deprived of their freedom.

• At one stage the majority of patients were involved - delaying certificates as they all went to Coroner, who would issue a certificate if we provided information on the patient / diagnosis.

• This did cause delays and had to be explained to families.
Some local experience

• now pts are asked on admission if they agree to the admission and if they would agree to have medication at the end of life that could cause them to be more drowsy.... If they agree to this there is a reduced risk of someone suggesting a DOLS

• This has reduced DOLS to those for whom the conversation is not possible, those who have lost capacity before / on admission, those who do ask to leave (very small number).

• As most DOLS are at the end of life the urgent form is completed and hardly ever is authorisation granted as there are enormous delays (weeks) from the DOLS office.”
Association for Palliative Medicine survey 2015

- 155 people completed: 80% worked in a hospice
- 146 (94%) reported discussion of a policy and 112 (75%) reported a policy in place
- Comments included:
  - "A huge amount of time and effort has been diverted from patient care to reviewing DoLS implications. Social work and quality departments are pushing for a to-the-letter adherence, which is at odds with clinicians wanting to deliver patient-centred care rather than defensive practice."
- Use of DoLS for an unconscious patient, who has lost capacity at the end of life
  - 12 (9.8%) reported that their organisation was using the legislation in this way
  - 110 (90%) were not using DoLS for all unconscious patients
• 50% felt that the use of the DoLS caused distress to families

• 40% felt the DoLS caused delays for families in making arrangements
Upshot: variable practice – big impact.

• The sensitive discussion/paperwork/time involved in applying for a DoLS gives added strain to an already busy workforce.

• The cost:
  • Assessment by 2 independent experts charged to local authorities. Each assessment costs £1,377 and is place-specific and time limited (longest allowed period = 12m) with renewal required in the individual moves/the time limit passes. EJPC 2016; 23(2)

• Does it give added value?
  • or does it detract from the desired focus of care - preparing for dying

• Death demands a Coroner’s investigation and inquest because death under a Deprivation of Liberty Safeguard = death in custody
  • What is that like for families?
  • How prepared are they?
In hospitals:

- Inconsistent practice
- Poor follow through after urgent authorisations
- In last 1 yr no patient has arrived at SFH from hospital who had a DoLS authorised in hospital.
- From EJPC 2016; 23(2):
  - 2014-15:
  - 40% of hospital applications not processed
In care homes:
By far the highest number of applications for DoLS are made by care homes - 69% of all applications CQC 2013/14
In care homes

• Original estimates of DoLS application:
• In England:
  • 2000 people/yr
• 2009-10
  • 7,157
• 2014-15
  • 137,540 applications.
  • 80% were over 80 years old.
  • 51% related to with dementia
  • Most died within months
  • Huge impact on Coroner system
At home:

- E.g. supported living, adult placement/shared lives or domiciliary care: an application must be made to the Court of Protection.

- Care providers (where appropriate, with local authority care managers) should examine the situation of people who lack the mental capacity to agree to their living arrangements, to see if they appear to be deprived of their liberty in the light of the Supreme Court judgement. They may wish to seek legal advice, and liaise with the commissioners of the service, if they think they might be depriving someone of their liberty and cannot find a less restrictive option for providing care or treatment.
At home Scenario 1

An older person with dementia is living at home with considerable support. Staff monitor her well-being continuously at home because she forgets to eat, is unsafe in her use of appliances, and leaves the bath taps running; she is accompanied whenever she leaves her home because she forgets where she lives and is at risk of road accidents or abuse from others.

She shows no sign of being unhappy or wanting to live elsewhere, but, in her best interests, she would not be allowed to leave to go and live somewhere else even if she wanted to. CQC 2014
At home  Scenario 2

An older person with a brain tumour is living at home with considerable support. An feature is that he is ‘on the move’ for long spells through the day. He cannot say why.
He is becoming progressively more unable to mobilise safely: a home carer has been walking with him (around his house/latterly around the room) but now every time he attempts to stand his legs buckle. Constantly wanting to stand and take off
He cannot be left
He does not seem unhappy: just very fixed on moving.
What to do? CM 2015
Case Law to help us

- Queen V HM Senior Coroner for inner London and Kings College Hospital NHS Foundation Trust (2015) EWHC 2990

- Indicates the majority people in ICU or hospices that lack capacity would not be considered deprived of their liberty

- Not a deprivation of liberty due to
  - the short period of time (less than 3 weeks)
  - Family were actively involved and supportive of care and treatment.
  - Care and treatment was urgent and life-saving

- 11/08/2015
However each case should be judged on its own merits. Consider DoLS if:

- There is **serious debate** to proper treatment.
- **Active resistance from family** or particular course of treatment.
- **Active resistance from person** (lacking capacity) to the treatment.
- **Family or friends ask to discharge** the person and this is **refused**.
- **A person** (lacking capacity) asks to discharge themselves or physically tries to and is confused
What now?

• Providers of hospice, palliative and end of life care have called for urgent clarity around Deprivation of Liberty Safeguards applications for people under their care, and a cross party commitment to a review of the legal framework.

• Particular advice from the Department of Health and the work of the Law Commission, and the Law Society.
• **August 2015:** The Law Commission review of DoLS begins. New legislation replacing DoLS with new procedure planned for 2018/2019

• The Law Commission’s [consultation on proposals for the reform of the current framework for Deprivation of Liberty Safeguards](https://www.gov.uk/government/consultations/consultation-on-proposals-for-the-reform-of-the-current-framework-for-deprivation-of-liberty-safeguards) (DoLS) was open until 2 November 2015.

• The Law Commission’s consultation is looking at how deprivations of liberty, for people who lack capacity to consent to care and treatment, are regulated by law and how this law can be improved.
What we can do meanwhile

- Where possible gain patient’s consent to care and treatment before they lose capacity to consent to care and treatment. This needs to be documented.
What we can do meanwhile

- Education/support for police concerning ACP
- Keeping in touch with local coroner arrangements
  - All deaths must go to inquest – distressing delay for families affecting their bereavement. Particularly for people whom culturally a swift burial following death is required.
  - “when a person who is subject to an authorisation dies naturally, in circumstances that are uncontroversial, the inquest may be a “paper” inquest, decided in open court but on the papers only, without a witness having to attend” (Chief Coroner 2014)
  - Inquests after death should be explained to families in advance of DoLS authorisation.
- Patient and family/carer leaflet or information about Deprivation of Liberty Safeguards.
The end!