

Background:

The East Sussex Local Safeguarding Children Board (LSCB) (now the East Sussex Safeguarding Children Partnership (ESSCP)) undertook a Serious Case Review (SCR) of Child T who died in hospital at the age of 18 due to a complication caused by his diabetes. Child T lived with his mother and was an only child. He was diagnosed with Type 1 diabetes at the age of 13. He went in to hospital three months before he died. The condition he was in was shocking; he was in an extremely poor state both physically and emotionally, and showing signs of severe neglect. His death was sudden and unexpected.

Sharing learning is a key priority for both the ESSCP and the East Sussex Safeguarding Adults Board (SAB). The SCR identified important learning for SAB partner agencies, particularly concerning the areas of self-neglect, mental capacity, inherent jurisdiction, coercion and control, and transitions between Children's and Adults Services. This briefing sets out the key findings of the SCR and summarises key learning in these areas. All staff and managers are encouraged to discuss this briefing and the learning and reflection points, to ensure that learning outcomes are used to consolidate best practice.

You can access the full [SCR report](#) on the [East Sussex Safeguarding Children Partnership](#) website. An [additional briefing](#) published by the ESSCP is also available on the website.

The key findings of the Serious Case Review

Mental Capacity relating to 16 / 17 year olds

Whilst the MCA applies from the age of 16 years, in this case there was no consideration of Child T's mental capacity prior to his hospital admission, despite concerns about decisions that were being made in respect of Child T's attendance at school and health appointments, and engagement with medical treatment. There was also an opportunity to consider a MCA assessment for Child T's mother as a carer due to concerns about her mental capacity in relation to Child T's needs and her seeming inability to understand his type 1 diabetes.

Decision-making in respect of young people aged 16 – 17 differs from adults in that there are circumstances in which parents and others with parental responsibility are able to make decisions on behalf of their child up to the age of 18. Although the MCA applies to those aged 16 and 17, in some areas there are significant differences in how the MCA provisions apply to young people as opposed to adults over the age of 18.

A **Serious Case Review (SCR)** is a locally conducted multi-agency **review** in circumstances where a child has been abused or neglected, resulting in **serious** harm or death and **there** is cause for concern as to the way in which the relevant agency or agencies have worked together to safeguard the child.

The purpose of a SCR is to:

- Establish whether there are lessons to be learned about the way in which local professionals/agencies work together to safeguard children
- Identify what needs to be changed and
- Improve inter-agency working to better safeguard and promote the welfare of children / young people.



Parental Responsibility

The Mental Health Act (MHA) Code 2015 includes guidance on the scope of parental responsibility:

- Parents should not be relied upon when the child is competent or the young person has capacity to make the particular decision.
- Where the child is not competent, or young person lacks capacity, the question of whether the parents can consent to a particular decision will need to be assessed in the light of the particular circumstances of the case, taking into account:
 - Is the decision something that a parent 'should reasonably be expected to make' (covering points such as the type and invasiveness of the proposed intervention, the age, maturity and understanding of the child / young person and whether the child / young person is resisting the decision).
 - Are 'there any factors that might undermine the validity of parental consent', such as whether the parent(s) lack capacity to make the decision or is unable to focus on what course of action is in the child / young person's best interests.

Self-Neglect and Mental Capacity: Self-neglect had not been identified as an issue for Child T until his admission to hospital, when the hospital and ambulance service raised safeguarding concerns due to his extremely poor physical state.

It can be a difficult balance for professionals between supporting a person to make decisions for themselves which may be unwise and protecting them from risks associated with self-neglect.

Self-neglect needs to be understood in the context of each adult's life experience. It is a complex interplay between physical, mental, social, personal and environmental factors. It is likely that self-neglect is the result of some incident or trauma experienced by the adult, for example childhood trauma, bereavement or abuse. This may also lead to a person becoming demotivated and developing a poor self-image and self-esteem, which will impact on their ability to engage with professional support. Positive outcomes can be achieved through approaches informed by an understanding of the unique experience of each person. It is imperative that all multi-agency practitioners remain non-judgemental, and have a shared and compassionate approach to understanding the complexity of the adult's history and background and how this has led to their current circumstances.

The Mental Capacity Act 2005 (MCA) is crucial in determining what action may or may not be taken in self-neglect cases. The MCA is designed to protect those who cannot make decisions for themselves, and is underpinned by human rights principles which aim to ensure its provisions are applied in a way that respects our human rights.

MCA - Five Statutory Principles

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is **less restrictive** of the persons rights and freedom of action.

4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his **best interests**.

3. A person is not to be treated as unable to make a decision merely because he makes an **unwise decision**.

2. A person is not to be treated as unable to make a decision unless **all practicable steps** to help him to do so have been taken without success.

1. A person must be **assumed to have capacity** unless it is established that they lack capacity.

An adult should be presumed to have capacity.

However, there may be cases where an adult may lack understanding and insight into the impact of their self-neglecting behaviour on their or others' wellbeing.

When an adult's behaviour or circumstances cast doubt as to whether they have capacity to make a decision, then a mental capacity assessment should be carried out.

You can find some tips on good practice when conducting mental capacity assessments on the next page.

Good practice tips for mental capacity assessments

- When assessing the mental capacity of an adult who is self-neglecting, consider carrying out joint capacity assessments, for example, involving an occupational therapist, nurse or psychologist working alongside a social worker.
- Any mental capacity assessment must be time-specific and relate to a specific intervention or action.
- Provide information in an appropriate format and use communication methods which the person is most familiar with.
- Record the actual questions as they were asked and the responses provided.
- Consider whether having another person present (such as a family member or friend) would help the person. Consider whether there is a duty to provide an Independent Mental Capacity Advocate (IMCA) or independent advocate under the Care Act 2014.
- The consideration of support from another individual has to be balanced alongside professional judgement as to whether the individual involved may exert undue pressure or coercion.

It is important to clearly document how a worker has maximised an adult's autonomy and involvement within the capacity assessment, ensuring they have been given all practical support to help them reach a decision for themselves. In relation to self-neglect, this will include exploration of the adult's understanding of their behaviours and associated risks:

- Can they report back to you what the risks are?
- Can they report back to you that they know their behaviour places them at risk?
- Can they report back to you the consequences of taking these risks?

Adults who self-neglect may be reluctant, or find it difficult, to engage in the assessment of capacity.

Further guidance on engagement can be found in section 2.8.5 of the Sussex Multi-agency Procedures to support adults who self-neglect

What factors can affect mental capacity?

Child T had complex and significant health problems, including unstable diabetes and urinary infections. These physiological issues can have an impact on mental capacity and should always be considered by professionals when undertaking MCA assessments. It is important to carry out capacity assessments and provide support at a time when the person is at their highest level of functioning.

Child T had a complex relationship with his mother, marked by co-dependency and signs of control and coercion by his mother. It was hard for professionals to hear and listen to Child T's voice. He would frequently look to his mother to answer any questions. Child T's mother would often not adhere to medical advice and was insistent on undertaking her son's care herself.

The impact of both of these areas was an important consideration in Child T's ability to make informed decisions and choices about his care and treatment.



Inherent Jurisdiction

The High Court is able to intervene in the life of a vulnerable adult who possesses capacity but still requires protection for certain reasons. This includes not being able to take a decision freely because of coercion, undue influence or constraint. Child T could have been identified as such a vulnerable adult, if legal advice had been sought in this case by health or social care professionals.

Taking a case to the High Court for a decision regarding interventions can be considered in extreme cases of self-neglect, i.e. where a person with capacity is:

- at risk of serious harm or death, and
- refuses all offers of support or interventions, or
- is unduly influenced by someone else.

The High Court has powers to intervene in such cases, although the presumption is always to protect the adult's human rights.

Legal advice should be sought before taking this option.

Transition between Children's and Adults Services

NICE guidelines were published on transition in February 2016. These note the importance of a planned and coordinated approach to support the transition between Children's and Adults Services for a young person with care and support needs. The guidelines suggest that a single practitioner should act as a 'named worker' to aid a smooth transition, who ideally should be a worker who has developed a meaningful relationship with the young person.

It is acknowledged that once young people have transitioned to adult services there is potentially a need for support after transfer. NICE states that if a young person has moved to adult services and does not attend meetings, appointments or engage with services, adult health and social care, working within safeguarding protocols, should:

- try to contact the young person and their family,
- follow up the young person, and
- involve other relevant professionals, including the GP.

Professionals need to remember that a person is a child until they are 18 years old. Appropriate safeguarding supervision should be sought and children's procedures followed when required.

Key learning points for reflection and team discussions

Do you work with people (including young people aged 16-18) who may lack capacity to make certain decisions?

How would you approach this?

Do you know how to get the support you need?

Are you and your team familiar with the Sussex Policy & procedures on self-neglect?

Are you confident in recognising self-neglect?

Are you confident in recognising signs of coercion and control?

Do you need more support or training?

Further information

[Sussex Safeguarding Adults Policy and Procedures](#)

[Sussex Multi-agency Procedures to support adults who self-neglect](#)

[Mental Capacity Act Code of Practice](#)

[SAB briefing on Self-neglect](#)

[East Sussex Learning Portal](#) – for access to training on Self-neglect and Coercion and Control

The East Sussex SAB published a Safeguarding Adults Review (SAR) in October 2017 regarding Adult A. The case involved issues of self-neglect and mental capacity. Learning from that case is also relevant to Child T. The [learning briefing](#) in relation to the Adult A SAR is available on the [East Sussex SAB website](#)

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