NHS
Somerset
Clinical Commissioning Group

Report to the NHS Somerset Clinical Commissioning Group on 31 March 2022

Title: Patient Story (Becca's story)	**Enclosure H**

Version Number / Status:	1.0
Executive Lead	Val Janson, Director of Nursing
Clinical Lead:	NA
Author:	Emma Savage – Deputy Director of Quality and Nursing

Summary and Purpose of Paper –

This presentation provides an overview of Becca who had a cardiac arrest at the age of 34 and was diagnosed with Prolonged Disorder of Consciousness.

Becca went on to live in a care home for 13 days, funded by Continuing Health Care.

In 2020, following a conversation with Becca's family and the professionals who provided medical oversight a decision was made that it was in the 'best interests' for Becca for her life to end in a planned way.

Becca's life ended in a peaceful way in October 2021.

Due to the complexity of this case and the learning for all those involved, including Becca's family, the CCG's Director of Nursing request a learning review.

A learning review took place in February 2022 with Becca's family and the care professionals who supported her. Below is a summary of the learning and actions being taken by the CCG to help make a difference to others who may be in a similar circumstance to Becca.

Recommendations and next steps

The Governing Body are asked to note the actions being taken following this learning review:

- To audit the CHC caseload to make sure we are asking the right questions
- Raise Awareness across CHC teams nationally
- Introduce mandatory Mental Capacity Act training and a competency assessment. The Somerset CHC team are to pilot this, with the expectation that it will be picked up across the county
- PDOC training day coming to Somerset

- Incorporated a new priority into YDH's and SFT's Quality Schedules 22/23 '*For any patients who lack capacity to have a 'best interest' meeting prior to discharge from inpatient neuro rehab services'*
- Present Becca's story to the CCG's Governing Body

Impact Assessments – key issues identified				
Equality	NA			
Quality	This report highlighted the need for improvement in the decision making processes for those who lack mental capacity.			
Privacy	Becca's family have agreed to sharing her story and want it to be used to help make a difference to other patients and their families			
Engagement	The preparation for this learning review involved much engagement with Becca's family, colleagues at SFT, YDH and NHSEI. All were actively involved in the learning review.			
Financial / Resource	NA			
Governance or Legal	This learning review follows Prolonged Disorder of Consciousness clinical guidelines and the Mental Capacity Act. Advice was also sought from the national clinical lead for Prolonged Disorder of Consciousness.			
Risk Description	Any risks regarding the decision made for Becca's life to end were proactively and sensitively managed at the time.			
Risk Rating	Consequence	Likelihood	RAG Rating	GBAF Ref
	Low	Low	Green	

The Story of Becca

Emma Savage, Deputy Director of Quality & Nursing

NHS Somerset CCG

March 2022

A bit about Becca

- Rebecca Smith liked to be known as Becca , she was a middle sister of a Somerset family, she loved to be outdoors and had an adventurous spirit

Becca's medical history

- In 2008, Becca aged 34, fell whilst climbing out of a window resulting in a fractured hip. Two weeks later she had a seizure and cardiac arrest, she was given CPR by her dad but she remained unconscious
- Becca was assessed by Neurological teams and diagnosed as having hypoxic brain injury and remained in a minimally conscious state
- Becca was given a diagnosis of Prolonged Disorder of Consciousness (PDOC)
- Becca showed no improvement in her condition and required all her care to be anticipated
- Following a Continuing Health Care (CHC) assessment, in 2009, Becca was admitted to a care home in Yeovil where she lived for 13 years
- Becca had a yearly review of her health needs by the neurology department at Somerset Foundation Trust and an annual CHC review

Becca's health needs

- Becca remained unconscious and as a result she could not communicate in any way and any means
- She had a Percutaneous Endoscopic Gastrostomy (PEG) feed and this was used to provide all her hydration, nutrition and medication
- Becca received Botox and physio to help manage contractures to her limbs and had Insulin dependant diabetes
- From February 2019, Becca started to have frequent emergency admissions into hospital for pneumonia and later sepsis
- 'Best Interest' discussions started to take place in the summer of 2020 in consultation with Becca's family and the health and care professionals supporting Becca
- A decision to withdraw treatment was approved by YDH's Ethics Committee in May 2021
- Becca died in a planned and peaceful way at St Margaret's Hospice at the age of 47 in October 2021

Learning Review about Becca

In February 2022, initiated by the CCG Director of Quality and Nursing, we undertook a learning review with the support of NHSEI, Becca's family and the health and care professionals who supported Becca.

Below are some of the insights we learned about Becca, her life and the decisions that were made:

- Becca's family felt that they lost her at the time she had her cardiac arrest, some 12 years previously, and had not been able to mourn. They believed Becca was leading a life she wouldn't have wanted
- There were differing views within the family, with her father convinced she would get better, making a 'Best Interest' discussion difficult to have
- The family reflected that the decision for Becca's life to end was one that had been made collectively by the family and professionals involved. It was important to know and it was appreciated that Becca's mother didn't carry the sole responsibility for the decision that was made

What did we learn about Becca's Review (1)?

- That the Mental Capacity Act needed to be applied at the beginning and throughout Becca care
- That we need to ask questions to find out the answers. Would Becca have valued the life she was living, what would she have wanted?
- Reaching a decision that it is not in someone's best interests for them to continue to receive CAHN and deciding to withdraw treatment are two different things
- In 2018, the law changed in relations to CANH. Now when everyone is in agreement about what is in a persons best interest the Court of Protection is not required and a robust Best Interest process is the lawful process

What did we learn about Becca's Review (2)?

- That the real learning is that this is not about changing our approach to people diagnosed with PDOC, we need to change our approach to anyone who lacks mental capacity to consent to treatment
- Becca family wished that they had been invited to more meetings and reviews so they understood and stayed involved
- Careful use of language was important
- That case coordination requires people to take identified leads, the role of the complex care nurse was really valued in Becca's care
- A better understanding of the meaning of Next of Kin
- Clinicians need Mental Capacity Act training at the right level to undertake their roles and this ideally needs to be competency assessed

The actions we are taking in Somerset

1. To audit the CHC caseload to make sure we are asking the right questions
2. Raise Awareness across CHC teams nationally
3. Introduce mandatory Mental Capacity Act training and a competency assessment. The Somerset CHC team are to pilot this, with the expectation that it will be picked up across the county
4. PDOC training day coming to Somerset
5. Incorporated a new priority into YDH's and SFT's Quality Schedules 22/23 '*For any patients who lack capacity to have a 'best interest' meeting prior to discharge from inpatient neuro rehab services'*
6. Present Becca's story to the CCG's Governing Body