

## **'I just wanted answers. It was excruciatingly long': Causes and Solutions for the Perinatal Pathology Crisis in England – a briefing by Sands**

### **Introduction**

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We are calling on the Government to take urgent action to fix the ongoing crisis in Perinatal Pathology. All parents should receive accurate, timely and sensitive communications from trained healthcare professionals about perinatal post-mortem services and the options available to them. No parent should wait longer than six months for their baby's post-mortem to be undertaken and the results communicated to them.

The widely acknowledged critical shortage of perinatal pathologists across the UK is having a devastating impact on parents. At Sands we hear regularly about the heartbreak caused by lengthy delays, by poor communication and about a lack of choice or control. This shortage has grown over decades, leading to the current crisis in the delivery of perinatal post-mortem services.

In recent years mutual aid between pathology centres has worked to reduce the impact of the shortage of pathologists, but that approach is increasingly breaking down as overburdened centres have dwindling capacity to pick up cases beyond their own area.

NHS England is considering how to address this crisis at a national level. This includes introducing a new policy for the commissioning of perinatal post-mortem services. Meanwhile a recruitment drive and plans for service re-organisation are on-going but will take significant time to have an impact. Sands has fed into various NHS England initiatives, but we are increasingly concerned that user needs are not yet sufficiently prioritised.

### **The current situation**

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#### **1. Interim triage policy**

In October 2022, an interim policy for the commissioning of perinatal post-mortems was adopted across England, Wales and Scotland. The policy defines inclusion and exclusion criteria for which cases will be offered a perinatal post-mortem and which will not. This approach is based on research evidence which shows that in many cases a full post-mortem only gives limited additional information compared with less invasive post-mortem options.

While the interim policy says liaisons between healthcare staff and parents will determine which investigation is appropriate, we have concerns about the lack of guidance on implementation. We have also highlighted the need for clear communication of the policy to all consent takers.

Since publication of the policy, there has been no audit of uptake or impact. NHS England acknowledges that communication of the policy has fallen short. Sands has received many anecdotal reports of consent takers being unaware of the new approach. We are concerned this is leading to parents not being fully informed about consent. A full policy review is currently being carried out, but Sands has not been invited to contribute and we are unclear user input is expected.

#### **2. NHS England Perinatal Pathology Transformation Programme**

NHS England has recently established a programme to examine and action options for increasing capacity and choice in perinatal post-mortem services across England, including to bolster recruitment to increase capacity (though approaches to date have been unsuccessful, suggesting a

deep-rooted problem), and expand availability of Minimally Invasive Autopsy (MIA) and other non-invasive techniques. These techniques are currently only available in a small number of centres.

Sands is contributing to the Steering Group overseeing the workstreams but is increasingly concerned that there remains too little focus in the delivery on the needs of parents and families, be that for timely and accurate information or for timely investigations and reporting.

### **3. Royal College of Pathology (RCPATH)**

The RCPATH has a specialist Perinatal Pathology Sub-Committee. The chair presented on workforce issues to the Maternity and Babyloss APPGs in 2022 and March 2023, describing a new recruitment campaign and plans to revise their training program.

Sands is supportive of this and would like to see progress on the RCPATH proposals for growing the workforce, in the immediate and the longer term.

#### **NHS England must provide:**

- A parent pathway to sit alongside the triage policy, laying out clearly what parents' choices are, when they will be consulted, how their preferences will be heard, when and by whom, and what the process is if agreement is not reached.
- Clarity that parents' wishes will be prioritised when at odds with the pathologist's.
- Revised information resources to ensure parents and healthcare staff have consistent and clear, locally relevant information about how the policy will be implemented for them.
- An active communications strategy to ensure all healthcare professionals who are interacting with bereaved parents, in particular consent takers, are familiar with the triage system.
- That the professional discussing the post-mortem choices with the parents must be familiar with the National Bereavement Care Pathway and standards, and local support options.

#### **The Government must:**

- Set out how they plan to ensure that Perinatal Pathologist recruitment is prioritised in NHS workforce planning and that no parents ever have to wait more than 6 months for post-mortem results.

#### **MPs can help by:**

- Writing to Steve Barclay, Secretary of State for Health and Social Care asking for urgent action to ensure that Perinatal Pathologist recruitment is prioritised and that no parent ever has to wait more than 6 months for post-mortem results. Please forward any responses received to [campaigns@sands.org.uk](mailto:campaigns@sands.org.uk).
- Raising the issue in Parliament.
- Joining the APPG on Baby Loss to work with other MPs on this problem.

**For more information, contact:** [campaigns@sands.org.uk](mailto:campaigns@sands.org.uk)