

## Briefing from Sands for the General Debate on Baby Loss Awareness Week

### The Crisis in Perinatal Pathology Services

19<sup>th</sup> October 2023 – Main Chamber, House of Commons

#### Introduction

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Sands welcomes the annual General Debate to mark Baby Loss Awareness Week and its return to the Main Chamber.

For Baby Loss Awareness Week this year, we are calling on the Government to take urgent action to fix the ongoing crisis in perinatal pathology, so no parent ever has to wait for more than six months to find out why their baby died.

#### The current crisis in perinatal pathology

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It's widely acknowledged that perinatal pathology in England is in crisis, and there is urgent need to address this. Currently, a significant proportion of parents have to **wait over three to six months** for their baby's post-mortem to be undertaken and for the results to be communicated to them. For some the wait extends to **over six months and even over a year**. Too often the impact on parents of lengthy waiting times is further exacerbated by poor communication about what is happening and a lack of choice or control. A post-mortem offers a possibility of answers, even if this is to rule things out. Yet parents are being left in distressing limbo, unable to move on with their grief, and lacking important information which can determine difficult decisions about another pregnancy. It is unsurprising that the widely acknowledged critical shortage of perinatal pathologists across the UK is having a devastating impact on parents.

The shortage of perinatal pathologists has been growing over decades. In most recent years mutual aid between pathology centres reduced the impact on national delivery of services, but that approach is breaking down as overburdened centres have dwindling capacity to pick up cases beyond their own area.

NHS England is taking some steps to address the problems, including introducing a new policy for triaging the delivery of perinatal post-mortem services. Meanwhile a recruitment drive and plans to use new technologies 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 the needs of bereaved parents are not yet sufficiently prioritised.

**Question to raise: What additional resources and support will the Government provide to ensure that the needs of bereaved parents are being prioritised?**

## Parents Voices – Sands survey of bereaved parents

In June 2023 we launched an online survey asking bereaved parents about their experiences of care, receiving almost 2,000 responses. We wanted to capture the current state of maternity care, including parents' experiences of post-mortem services. We found that delays in parents receiving post-mortem results have significantly worsened over time, and particularly in the last three years.

**Almost a quarter (21%)** of parents reported **waiting up to six months** or more for the results of their baby's post-mortem. Almost all parents who consented to a post-mortem spoke about long waiting times and the significant and damaging impact that has had on them. For some parents, these delays mean they cannot plan for another child.

**Question to raise: Will the Government provide a clear commitment and timeline for the recruitment of perinatal pathologists to ensure that no bereaved parent ever has to wait more than 6 months for post-mortem results?**

## The Current Situation

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### A Interim Policy Review

An interim triage policy for the commissioning of perinatal post-mortems was adopted in October 2022. The policy defines 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.

Since the adoption of the interim triage policy, there has been **no audit of impact** on the service or on parents. NHS England has acknowledged that communication of the interim policy has fallen short. Sands has received many anecdotal reports of healthcare professionals who take consent for post-mortems being unaware of the new approach. We are concerned this has led to parents **not being fully informed about consent**.

A full review of perinatal pathology guidelines is being carried out, with revised guidance expected to be published within months. We believe this new policy must include a robust parent pathway with parents' needs and entitlements clearly set out and communicated.

### Questions to raise:

- **What steps will the Government take to ensure that every parent will be fully informed about new post-mortem procedures in order for the consent to always be fully informed?**
- **What is the progress of the full review of perinatal pathology guidelines?**
- **Will the new guidelines include a pathway setting out parents' entitlements?**

### 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. This includes **bolstering recruitment to increase capacity**, though the lack of success of approaches to date suggest a deep-rooted problem. There are ambitions to **expand availability of Minimally Invasive Autopsy (MIA)** and other non-invasive techniques which can speed up the post-mortem investigation and are

preferred by many parents. These techniques are currently only available in a small number of centres and will take time and resource to roll out further.

Sands is contributing to the Steering Group overseeing the workstreams but is concerned that there must be a sharper focus on the needs of parents and families, both to ensure the provision of timely, accurate and sensitive information, and for timely investigations and reporting.

#### Questions to raise:

- **How will the Government ensure that the needs of the parents and families are a priority focus in the NHS England Perinatal Pathology Transformation Programme?**
- **What measures will the Government put in place to ensure timely, accurate and sensitive information, and timely investigations and reporting, are always upheld in perinatal post-mortem services?**
- **How will the Government support the further roll out of Minimally Invasive Autopsy (MIA) and other non-invasive techniques in order to expand their availability into all centres?**

#### New Recruitment Campaign

The Royal College of Pathologists (RCPATH) has a specialist Perinatal Pathology Sub-Committee. The chair has presented on workforce issues to the APPGs on Maternity and Baby Loss on a number of occasions, most recently last month, describing a **new recruitment campaign and plans to revise their training program**.

Sands supports this. We would like to see progress on the RCPATH proposals for growing the workforce, in the immediate and the longer term. We also want to see **a parent pathway embedded** within their new guidance setting our **clear rights and entitlements** for bereaved parents.

**Question to raise: What action will the Government take to ensure perinatal pathologist recruitment is being prioritised in the NHS workforce?**

#### About Sands

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Sands works across the UK to support anyone affected by the death of a baby, improve the care that parents receive from the NHS and reduce the number of babies dying.

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