Death before Birth

Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth

death before birth

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Overall project aim:

To examine the law surrounding the disposal of the remains of pregnancy and the ways in which it is interpreted, and to examine the narratives of women and those who support them, focusing on metaphor as a commonly-used resource for expressing the inexpressible.

We are grateful to the ESRC for funding this research. Award Number: ES-N008359-1

What we did?

Documentary analysis

- Review of Trust policy documents

Interviews with:

- people who provide support to the bereaved
- women who have experienced miscarriage, termination due to fetal anomaly, stillbirth
- people (partner, friend, family member) who have supported a bereaved woman

Focus groups

- with women who have experienced miscarriage, termination due to fetal anomaly, stillbirth

Report on the Human Tissue Authority Guidance:

- How has HTA 'Guidance on the sensitive disposal of pregnancy remains' from March 2015 been incorporated into **other guidance documents**?
- Do **Trust policies** on the disposal of pregnancy remains take into account the HTA Guidance?
- Are the **recommendations** put forward in the HTA Guidance from March 2015 incorporated within Trust practice?
- Are bereavement midwives and funeral professionals **aware** of the HTA Guidance?

Findings:

Options available for disposal of remains of pregnancy

	Routinely Available	Exceptionally Available
Cremation	47	3*
Burial	22	15*

*Exceptions include: at cost; for cultural or religious reasons; for recurrent miscarriage; if parents have a burial plot already; later gestational stages.

	Available	Explicitly 'no incineration'
Incineration	11	15

Findings

Private arrangements

Home burial

- 28 Trusts – information available
- 5 Trusts – discouraged home burial/ removal of remains from hospital
- 15 Trusts – either no information on home burial or unclear from documentation provided

Key findings

- **Generally women are being offered some choice for disposal of remains of pregnancy**
- **Trust policy on disposal of remains of pregnancy is often unclear or internally inconsistent**
- **Women were often not prepared about what to expect from the experience of miscarriage – this includes management of remains**

Why this matters?

"Obviously mine was, um, so mine stopped growing at six weeks but I was twelve to thirteen weeks pregnant cause my body hadn't realised that nothing was happening. **Um so so he said your only options are a cremation and that has to be on site erm and it's up to it whether you want to be there or not and then if you want but the remains to remain on site. And I was like right okay that makes no sense bothering to uh. I just thought oh why wouldn't it just go in with general like clinical waste if it's - if they're not deeming it as a thing?** So it sort of made no sense I was like is it a thing? Cause one minute it is a thing and the next it's not a thing?"

WP4-10/2017

"And **I didn't know what to do** I didn't know how to to cope with what was happening and I was in pain …. we had a **terribly awful** practical talk about what did we do next s**o we ended up flushing the toilet? Because I couldn't figure out how to do anything else**…"

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Recommendations

- A standardised approach is needed for providing information on options for disposal
- Clarification needed on what sensitive incineration means and its permissibility
- Policies should inform women of all disposal options
- PILs should provide clear information about options for disposal of pregnancy remains
- Clearer guidance needed for women who miscarry outside of the hospital

TAILORING DISCUSSIONS TO THE INDIVIDUAL PATIENT

- Some women want e.g. ceremonial disposal; others do not.
- Must engage in dialogue about what to expect – including disposal options
- Dialogue envisages a two-way discussion aimed at identifying what information the woman wants and when
- Standardised approach to aid tailoring to the individual

STANDARDISED INFORMATION PROVISION

- Miscarriage care pathway: policies, consent forms and patient information leaflets
- Risks: tick-box, de-individualize care
- But healthcare professionals find useful: ensures consistency and all information given
- Use to: frame discussions, record decisions and information provision

STANDARDISED DOCUMENTS: WHAT MIGHT THIS LOOK LIKE?

- Drawn from examples of best practice
- Support verbal discussion with written information
- Standardised care forms: disposal options; no decision; delaying decision/information; timescales
- Consent forms: information given; decision; reminders to give information in a quiet place, with time to reflect, read leaflets and ask questions

"It's a learning experience and the language around it is just so poor. That's what I've definitely learned throughout this whole ordeal.

The Importance of Language

References to language in interviews with the bereaved and those who support them

- "ALSO language you know … I don't like [the term] 'lost', 'lost my baby' you know parents say 'I didn't lose my baby my baby died'"
- "she had noticed the words spontaneous abortion and had said … like 'why was the word abortion on my medical notes I've never had an abortion?"
- "the medical terms we don't use like … 'the baby was incompatible with life' … those terms might be used with parents at the hospital"
- "using words like 'letting go' or 'moving on', 'closure', 'grief resolution' … people are very resistant to that idea because it's it sounds like you're trying to introduce some sort of sense of they've got to put it down and they can't and they won't"

Varied experiences

- “I wouldn’t’ve said foetus I’d’ve just said the pregnancy … I wasn’t able to say termination at the time but I would’ve said oh the pregnancy ended and that would’ve been more natural for me”
- “I had decided to try to think of him more of a pregnancy and less as a person and you have funerals for people”
- “I wanted her to have a proper burial and not be considered just remains.”

Examples of effective and less effective communication in patient information leaflets

Good management of expectations

- ‘It is important to bear in mind, however, that there may not always be ashes to scatter following the cremation of a baby’.
- ‘You should be aware that the amount of ash collected and returned is relative to the size of your baby plus the items placed with your baby’.
- ‘In many crematoria it is not possible to retain any ashes after the cremation of fetal tissue. However [PLACE] Crematorium is usually able to retain a small amount of ashes which may be scattered on their Children’s Garden of Remembrance or returned to parents on request’.

Clear explanation of available options

- ‘First and foremost, this was your baby, and you have the right to make arrangements for the funeral yourself’.
- ‘The hospital uses a special area at the local [PLACE] Cemetery for all our baby funerals. Your baby will have his or her own coffin with a name plaque on and will be buried in a communal grave with up to 16 other babies’.

Unclear language

- ‘Burial is only offered in a shared plot for specific religious reasons and will need to be discussed with the chaplaincy’
- ‘Please inform your Midwife if you would like your baby to be written into the book’
- ‘After examination the tissue will be returned to the hospital mortuary to be disposed of in a sensitive manner after 3 months’

Unclear language

- ‘Batch cremation’
- ‘Various forms of memorial are available at the crematorium’
- ‘Remains chosen for cremation’
- ‘As the gates close, silence is kept’
- ‘If you prefer to go home and think about things’
- ‘You may wish to have your baby at home for a short time before the funeral, or to visit your baby in the Chapel of Rest at the funeral directors. Sometimes funeral directors advise against this’

‘Prescriptive’ language

- ‘Cremation will… your own arrangements would…’
- ‘Most women (and their partners) choose to let the hospital deal with the disposal of remains.’
- ‘Most parents find it helpful to see and hold their baby’

Better:

- ‘If you would like to, you may wash and dress your baby’
- ‘You might also like to consider having your child laid to rest in a family grave with a grandparent or great-grandparent’.

Suggestions for HTA policy and inspections

- Policies should facilitate informing women of all disposal options:
  - Guidance for women who miscarry outside of the hospital
- Clarify what sensitive incineration means and its permissibility

- PILs should provide clear information about options for disposal of pregnancy remains
  - Check that information provided to patients is comprehensive and clear
  - Check for overly-prescriptive language

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Find out more about the project:
www.deathbeforebirthproject.org

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