

Citizen Participation and Public Petitions Committee

8th Meeting, 2023 (Session 6), Wednesday
17 May 2023

PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Lodged on 11 October 2021

Petitioner Ann Stark

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to review the Human Tissue (Scotland) Act 2006 and relevant guidance to ensure that all post-mortems—

- can only be carried out with permission of the next of kin;
- do not routinely remove brains; and
- offer tissues and samples to next of kin as a matter of course.

Webpage <https://petitions.parliament.scot/petitions/PE1911>

Introduction

1. The Committee last considered this petition at its meeting on [21 December 2023](#). At that meeting, the Committee agreed to write to invite coroners and pathologists to give evidence. It also agreed to invite the relevant Minister to give evidence on the issues raised in the petition.
2. At this meeting, the Committee will take evidence from Dr James Adeley, Senior Coroner (Lancashire); Dr Simon Beardmore, Consultant Radiologist (Lancashire); Ann Edwards, Coroner Services Manager (Lancashire and Blackburn with Darwen council); and Dr Mark Sissons, Consultant Pathologist (Blackpool Teaching Hospitals NHS Foundation Trust).
3. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

4. The Committee has received new responses from Wendy Millar and the Petitioner which are set out in **Annexe C**. Melissa O'Sullivan has requested to send the Committee a written submission.
5. Written submissions received prior to the Committee's last consideration can be found on the [petition's webpage](#).
6. Further background information about this petition can be found in the [SPICe briefing](#) for this petition.
7. The Scottish Government's initial position on this petition can be found on the [petition's webpage](#).
8. Every petition collects signatures while it remains under consideration. At the time of writing, 55 signatures have been received on this petition.

Action

The Committee is invited to consider what action it wishes to take.

Clerk to the Committee

Annexe A

PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Petitioner

Ann Stark

Date lodged

11/10/2021

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to review the Human Tissue (Scotland) Act 2006 and relevant guidance to ensure that all post-mortems—

- can only be carried out with permission of the next of kin;
- do not routinely remove brains; and
- offer tissues and samples to next of kin as a matter of course.

Previous action

I contacted my local MSP who is taking up my individual case but is also supporting my petition to achieve wider change.

Background information

My child died suddenly at home. As a result, there was a post-mortem. I thought it was a Grant & View but discovered not only was it a post-mortem but that, the brain, throat and tongue had been removed. I was horrified.

In the event of a sudden or unexplained death the Procurator Fiscal provides authorisation for a post-mortem, not the next of kin. I believe that this must change. *I also believe that brains should not be routinely removed.*

I was advised that the tissue samples taken belonged to no particular person and would be held as part of Medical Records. When I tried to

retrieve them, I was sent on a wild goose chase for ten months, all whilst grieving.

This is different from *England/Ireland & Wales*, where loved ones are automatically offered the samples back (perhaps to add to caskets). People can decline the samples, but at least they are given a *choice*.

Annexe B

Extract from Official Report of last consideration of PE1911: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems on 21st December 2022

The Convener: The next petition is PE1911, which is on a review of the Human Tissue (Scotland) Act 2006 as it relates to post mortems. We are joined by a number of people in the public gallery who are directly affected and involved. We are also joined by Monica Lennon, who has an interest in the petition.

The petition, which was lodged by Ann Stark, calls on the Scottish Parliament to urge the Scottish Government to review the 2006 act and relevant guidance to ensure that all post mortems are carried out only with permission of the next of kin; that brains are not routinely removed; and that tissues and samples are offered to next of kin as a matter of course.

At our previous consideration of the petition, we agreed to seek additional information from a number of bodies, and responses from them are included in our meeting papers.

The Royal College of Pathologists confirms that resource concerns are not the only or main reason for its disagreement with the proposal to automatically offer tissue samples to the next of kin. It reiterates the challenges regarding timescales and practicalities.

The chief coroner outlines the process of tissue retention and return in England and Wales, and includes a link to guidance on computed tomography scanning for the purposes of post mortems.

We have a written submission from Ann Stark, whom we thank for her assiduous contributions to our deliberations. Her submission highlights the use of body scanners as an alternative to post mortems, and additional information from her about their use has been summarised in the meeting papers that we have received and considered. She stresses the importance of people having a choice about how their body is handled and the importance of consent.

The committee has also received a number of written submissions from individuals in support of the petition and of the points that the petitioner has raised in written evidence.

As I said, we have Monica Lennon with us. Welcome once again to our proceedings, Monica. Before I open up the discussion to members of the committee, if there is anything that you would like to say in support of the petition, I invite you to do so.

Monica Lennon (Central Scotland) (Lab): Good morning, convener. I am grateful to the committee for the opportunity to speak about the petition again. I will avoid repeating points that I have made previously.

I join the convener in thanking Ann and Gerry Stark, who are in the public gallery. I thank Ann for lodging the petition and for all the work that she has done to get to this point. They have raised difficult issues that many people cannot even face talking about, but the committee has had a number of supportive submissions from individuals who have had similar experiences.

Committee members know what the petition seeks to do. On the additional information that the committee has had since we last met, the information from colleagues in England is really important, particularly the submission from the coroner. We can see that there is a different approach in other parts of the UK, and divergence can be a good thing. When we have families telling us that there are serious issues about consent, proportionality and dignity for the deceased and their families, we have a duty to look at those issues. I really welcome the additional work by the committee, and I think that the submissions that have been received are helpful.

I still have concerns about the resource and workforce pressures that are raised in the submission from the Royal College of Pathologists. Those issues go beyond this petition, and they merit further explanation. I would certainly like to hear more from the Scottish Government.

To recap, we are here because of Ann and Gerry, who are the parents of Richard Stark. Richard was only 25 when he died in June 2019. It was a sudden and unexpected death. The committee might recall that Ann and Gerry had to fight for a very long time to get answers. Richard's death certificate was changed about 18 months after he passed away, with the cause of death changed to being a suspected seizure.

Committee members will also be aware that the post mortem was very invasive. I know that this is not pleasant to hear, but, in the committee's papers, there are details about Richard's brain, tongue and other body parts being removed.

We have heard evidence about the use of scanners, particularly in different authorities in England. There are resource implications and costs to that, but we have heard how effective those scanners can be.

I am aware that the committee has been given a lot of information, but last week you got an email with a link to a video produced by professors at the University of Leicester. If you have not had a chance to look at that video—I think that it is only three minutes long—I would refer you to it.

On the aspect of the petition that relates to tissue and consent and the role of the next of kin, it should never take a family several months to find out what has happened to their loved one after death. In this case, we are talking about 65 tissue samples, and Ann had to fight the system to have those samples returned. This is going on and people are not talking about it—often because they do not know. Ann knew about it only because she was asking questions. That tells the committee that there are a lot of unknowns.

As you can imagine, it is difficult for Ann and Gerry to sit here today, so I do not want to add much more other than to say that we appreciate the work that the committee

has done so far. Ann has felt voiceless in the whole process. The committee has been the only forum in which these issues could be brought into the public arena, so we really welcome the work that has been done. We note that the chief coroner has highlighted a number of points, and I believe that there has been an offer to connect the committee with senior coroners who have experience of the scanning technology. It would be very worth while to pursue that.

I am happy to stop there, convener. Thank you.

The Convener: Thank you, Monica. Thank you also for offering comment on behalf of the petitioners on this very difficult and sensitive petition. Having considered the evidence on the petition, I can say that we take the issues that it raises very seriously and that we want to explore it further. I suggest that we invite coroners and pathologists to give evidence, because I would like to understand the differences in approach between Scotland and England and to bottom those out.

David Torrance: Once we have taken evidence from coroners and pathologists, I wonder whether we could invite the relevant minister to come before us to give evidence.

The Convener: We would therefore hear from coroners and pathologists and subsequently seek to hear from the minister in pursuit of the petition. Do colleagues have any other suggestions, or are we content to proceed on that basis? I see that we are content. We take the petition very seriously. We will keep it open, and it will obviously form a significant part of our workstream as we go forward. I hope that the petitioner feels that we are taking this seriously as we explore the issues raised and take oral evidence.

Annexe C

Wendy Millar submission of 13 March 2023

PE1911/KK: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

1. Opt out of ALL post mortems as you do with organ donation- as it is your body.
2. Murder cases - scanners and toxicology should be used
3. Samples needed for investigation should be taken by keyhole surgery as it would in the living
4. Samples should be offered back to the next of kin when death certificate is issued giving them the choice to accept or decline
5. No removal of brains, throats or tongues should be carried out
6. The word Unascertained should not be used on certificates it is meaningless "uncertain "should be used softer and less distressing for the family and everyone understands it

I give permission for this to be published

Wendy Millar

Petitioner submission of 11 May 2023

PE1911/LL: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

I plead that you, as MSPs, exercise your power to make essential changes to post-mortems and tissue retention processes. Some of you are new to the committee and this petition was born out of the sudden and devastating loss of my child, Richard.

Richard's post-mortem revealed shocking truths. Not only was it not the expected view and grant, but my child's brain, throat, and tongue had been removed without my knowledge or consent. The mental cruelty of invasive post-mortems on families and the disrespectful treatment of the deceased is disgraceful when there is an alternative available in digital scanners. As I conduct more research and speak to more individuals, I feel society has been turning a blind eye to this invasive medieval practice for years, as it is not their loved one being butchered. I had to ask if they had removed my son's eyes as they had removed everything else!

Regarding tissue samples, it is crucial to provide the next of kin with the choice to accept or decline their return upon issue of the death certificate. This should be routine and would ensure dignity and control in the face of tragedy. I endured an eleven-month-long and emotionally draining process. In stark contrast, other countries automatically offer these samples back to loved ones, giving them the choice.

Post-mortems, in non-suspicious cases should only be carried out with explicit next-of-kin permission. Digital scanning capabilities with accurate results are used globally, why not in Scotland to eradicate invasive techniques. I suggest our country goes further than digital scanners and adopts an opt-out option for post-mortem and tissue retention. This would resolve numerous issues, such as the current and future shortage of pathologists, financial savings, and the prevention of mental health issues among the next of kin. Just as with organ donation, we should have the right to choose.

The horror and grief were overwhelming for my family. I ran a business, drove a car, attended meetings and had a normal life. Due to what was performed on my child and the ordeal I went through, I no longer drive, I'm now a recluse, up at 3am or 4am to distract myself from the nightmares of what my child went through. I have spoken with many others like me who have also received a life sentence of grief and trauma due to these procedures. How do the people who perform such invasive and unnecessary post-mortems sleep at night with this on their conscience – they can have no conscience. The opt-out option would give us OUR human rights – your body belongs to YOU!

Please support a more compassionate and respectful approach with greater transparency and accountability.