Case Study

Retention of fetal remains

Referral process with Marie Stopes International (MSI) and UH Sussex

Focusing on the communication during the referral process with MSI and UH Sussex, specifically for women referred to them and maintaining an effective communication pathway allowing for wishes of the individual patient.

* Clients names have been changed in this case study

healthwatch West Sussex

Case Studies Story

Following a first round of IVF Lukas and Junta received the wonderful news "they were to become proud parents," an exciting time for them both. After a 20-week scan at their local hospital, University Hospitals Sussex NHS Foundation Trust (UH Sussex) they were urgently referred to the Fetal Cardiology Unit at The Evelina Hospital in London for a detailed ultrasound scan, where they received the devastating news that their unborn baby boy Isak had Critical Pulmonary Stenosis with the likelihood he would develop further complications and have a very short life expectancy. Lukas and Junta made the heart-breaking decision to terminate the pregnancy, feeling this would be the least bad option for baby Isak.

The following day back in West Sussex, Junta attended UH Sussex for further tests and a brief consultation with the clinical lead and screening midwives. A referral was made to Marie Stopes International (MSI) for Lukas and Junta to attend MSI's clinic in Essex four days later. The first appointment was for a consultation and medical preparation for the termination, where they requested information regarding receiving Isak's remains for cremation and were provided with an information sheet. The following morning the termination took place, and instructions were given to the staff to keep Isak's remains for cremation and for a sample of the placenta to be sent for genetic testing. Lukas also spoke with staff back at UH Sussex to confirm this and with a local funeral director.

Six days later Lukas and Junta received the devastating news from MSI that baby Isak's remains had been collected by their third-party contractor for disposal. The option of having a funeral for Isak had been taken away from them. This event triggered a Serious Incident Investigation, and a duty of candour letter was sent to Lukas and Junta by MSI.

Whilst trying to grieve for their devastating loss, Lukas and Junta knew what had happened was not acceptable and that they needed to complain. Not knowing how to start the often-difficult process of making an NHS complaint, Lukas contacted a senior complaints officer at their local CCG (now NHS Sussex) to ask for advice and support and he will always remember this call and the compassion shown to him at this distressing time. Lukas was also directed to Healthwatch West Sussex Independent Health Complaints Advocacy Service (IHCAS). The advocate contacted Lukas to start the complaints process. The complaint letter was submitted to NHS Sussex a month later.

The complaint focused on the communication during the referral process with MSI and UH Sussex, specifically, why were Lukas and Junta not informed that Isak's remains could be kept for cremation or burial and that many funeral directors provide this service for free.

Lukas and Junta wanted to understand how MSI had allowed a third-party contractor to dispose of baby Isak's remains, and ultimately what happened to baby Isak.

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Lukas and Junta's journey to become parents continued and they were almost ready to start their second round of IVF, when following a consultation at the fertility clinic the consultant asked for the results of the genetic testing. The genetic testing was discussed before and after the termination for the purpose of determining the presence or otherwise of an inherited cardiac condition that could affect future pregnancies. Lukas called the screening midwives at UH Sussex and asked about the genetic testing results. They agreed to follow up this request and later that day Lukas and Junta received the news the laboratory had been unable to undertake the tests on the placenta sample as it had been fixed in formaldehyde resulting in the specimen being rejected. This news was extremely upsetting for Lukas and Junta as it compounded the original mistake. The impact was that they faced additional difficult choices and worries in case they were fortunate enough to have a successful second round of IVF.

Lukas contacted the advocate at IHCAS again, and another NHS complaint letter was written, agreed, and submitted to NHS Sussex. This triggered another serious incident investigation. The complaint focused on the need to understand what had happened with the sample of the placenta, whether MSI had followed their procedures, why had MSI and UH Sussex not informed Lukas and Junta of the error and why had it taken Lukas' enquiry to find out about the error.

The first response letter and SI Report were received nearly three months later.

- MSI stated the complaint highlights the importance of effective communication, compassion, and empathy, and this is what MSI constantly strive to achieve but on this occasion had failed to do.
- Lukas and Junta found the medical language to be insensitive on paperwork from MSI such as the term "products of conception" and as a result MSI have changed their paperwork to "remains of the pregnancy"
- MSI acknowledge that Lukas and Junta should have been provided with written information including a consent form and the patient leaflet prior to the appointment in Essex. This would have given them more time to consider the options and to make final arrangements appropriate to the circumstances.
- On departure from MSI, Junta was given leaflets on contraception and some condoms. Lukas and Junta found this to be very insensitive as they longed for a baby. MSI have since confirmed this was not the correct course of action.

The results of the serious incident investigation were distressing reading for Lukas and Junta. MSI confirmed that once they had become aware the remains had not been retained at the Essex Centre, it was originally assumed that Initial, the company contracted to manage the remains had collected them in error.

The investigation established this was not the case and the failings were due to a divergence from MSI's internal policies and procedures.

The fetal remains should have been placed in a white anatomical container and stored in the freezer for collection by the funeral director, however the investigation found the Essex Centre did not have the right anatomical container on the day and therefore Isak's remains were placed into a clinical bag, labelled but placed in a yellow "sharps" container.

This was not recorded in the logbook, and neither was a note placed on the container indicating "for retention do not remove." As this action was not taken, Initial collected Isak and he was disposed of with other unwanted products of conception.

MSI unequivocally accepted responsibility for the failure to keep Isak's remains and offered Lukas and Junta an unreserved apology.

The second response letter and investigation report followed three months later, and this again was distressing reading for Lukas and Junta. Having agreed for the need for genetic testing, the placental sample taken by MSI would be kept in a "dry" container. The form was received for the testing at the Essex Centre, but it did not specify any requirements of how the sample should be placed into the sample pot.

The management team then consulted directly with the laboratory regarding date and time of collection. MSI confirmed most of their treatment centres do not store formalin, however the Essex Centre does and subsequently the placental tissue was placed into a sample container containing formalin before collection by the laboratory. The incident highlighted a lack of communication and a need to review the standard policies and procedure at MSI. The complaint investigation confirmed that both parties involved knew that the sample could not be evaluated but had failed to inform Lukas and Junta.

This only came to light when MSI was trying to find Isak's remains and when MSI spoke to UH Sussex, it was shared at this point that the laboratory was unable to complete the testing. This was six days after the termination, but Lukas and Junta were not informed until they contacted UH Sussex more than two months later, again demonstrating a lack of communication.

Learning From Complaints - UH Sussex

- When Lukas and Junta attended their appointment at UH Sussex, the contract with MSI was new and there was no prompt in place for staff to initiate discussions about fetal remains and whether families would like a cremation or burial for terminations performed elsewhere. The Trust have since put in place measures to ensure this conversation is now initiated with all patients choosing to have a termination of pregnancy.
- In light of the new contract with MSI, discussions are underway about the pathway for women referred to them and maintaining an effective communication pathway.
- A new proforma is being developed at the Trust for each referral to an external organisation with questions regarding the named nurse and their contact details and confirming that the clinic is aware of the wishes of the individual patient. As each clinic has a different process the Trust is confident that this will improve and streamline communication.
- Lukas and Junta requested that the pregnancy loss web page is updated to include the arrangements for handling baby's remains. The Trust is working with the IT midwife and the prenatal bereavement team to determine how best to incorporate this information on the pregnancy loss website.
- The Trust has reviewed the process with the forms from Viapath Laboratory for genetic testing, and in future staff will write on the sample form "do NOT add anything to POC and send in a dry pot" in order to prevent any miscommunication in the future.

As result of the concerns raised by Lukas and Junta staff at the Trust will now document on the screening database when they have contacted the laboratory and also include a date to follow up the contact when concerns have been raised about the viability of a tissue sample.

Learning From Complaints - MSI

- All requests for retention of fetal remains (e.g., patient, police) must be met, ensuring documentation in the patient record, labelling, and storing and logging patients' "fetal remains." This should be undertaken by the named nurse/midwife caring for the patient. Only qualified nurses and midwives are solely responsible for documentation.
- Under no circumstances should fetal remains for retention be placed in yellow anatomical containers but instead stored in labelled, appropriately sized white containers. A stock of different sized containers up to legal limit should be purchased and held at all MSI centres undertaking surgical abortion.
- All MSI centres to immediately purchase a small freezer to enable separate storage of products requiring retention and or/collection later and ensure robust processes for logging products into the freezer. Where possible these freezers should be able to be locked to prevent inadvertent collection alongside clinical collection. Once in place, under no circumstances must any fetal remains logged for collection by patient/police/funeral directors etc be placed in the general clinical freezer.
- Failure to retain fetal remains when requested is now a zero-tolerance incident (any occurrence is automatically escalated to the MSI UK Executive Team).
- The incident will be presented for shared learning across the organisation and will be presented at team meetings in MSI UK centres and regional governance partners to ensure this is shared with other centres.
- A Quality and Safety Alert Bulletin should be disseminated to team members outlining the correct processes and pathways to be followed for the management of fetal remains including the fetal anomaly pathway.
- The root cause to the failing for genetic testing was a lack of a clear process regarding the collection of fetal samples for genetic testing. All MSI centres must be fully aware of the requirements for genetic testing, including the equipment that is required.

Although the fetal anomaly Standard Operating Procedure (SOP) references the actions that should be followed if the antenatal service requests genetic testing, there needs to be a formal SOP to guide both MSI and NHS colleagues on the appropriate steps that ought to be taken. This SOP must include guidance on how the request is to be fulfilled if the patient is undergoing treatment in a different MSI clinic to the one that received the original fetal anomaly referral from the NHS.

Learning From Complaints - NHS Sussex

- NHS Sussex Planned Care Team will continue to collaborate closely with the teams at MSI and UH Sussex. They will have regular contract and quality meetings with all providers of health care, monitoring the performance and quality of services through health outcomes, patient comments and complaints.
- NHS Sussex Chief Nursing Officer to attend local resolution meetings with both providers to provide further assurance regarding actions that have been undertaken by them to reduce the chance of such an error happening again in the future.
- NHS Sussex conducted a desk top review of all incidents reported by MSI to identify if there are any themes for concern.
- There is also a monthly contractual meeting with MSI to ensure that NHS Sussex have comprehensive quality oversight of care provision.
- The Chief Nursing Officer will also chair the monthly quality review meeting with UH Sussex and there will be an agenda item on maternity services where assurance is gained on the quality of this.
- A revised care pathway and standard operating procedures are now finalised between MSI and partner agencies and NHS Sussex including primary care and maternity services. These have been developed in collaboration to reduce the risk of any recurrence of the experiences of Lukas and Junta.

Following the receipt of complaints response letters and with support from their advocate, Lukas attended a meeting with NHS Sussex Chief Nursing Officer and Chief Executive Officer. This meeting helped Lukas share his concerns and at the same time he was also able to share with NHS Sussex that the second round of IVF had been successful, and Junta was pregnant. NHS Sussex offered support by making the director of midwifery at UH Sussex the single point of contact for Lukas and Junta, meetings took place and support was also offered by NHS Sussex to Lukas and Junta regarding their concerns that they did not have genetic testing results. They were given access to a lead GP in relation to the Genetic Pathway.

Additionally, local resolution meetings took place with both MSI and UHSussex. This helped Lukas to ensure that all agreed actions had taken place. There was still one outstanding question which was “What happened to Isak’s remains?” This question was again brought up at the complaint resolution meeting with MSI and it was agreed they would work with Initial to find out the final destination for Isak. MSI managed to locate the destination where Isak was unwittingly disposed of, and this was shared with Lukas and Junta.

To end this sad and distressing case study with a positive outcome, Lukas and Junta welcomed a baby girl safely in July 2022.

Learning From Complaints - IHCAS

Since I was put in touch with Healthwatch, the advocate has been overseeing my case including bringing the right people together, chasing providers, preparing agendas, attending meetings, and keeping me informed throughout.

The advocate has been an outstanding advocate, always willing to listen and be guided by how I wished to proceed having laid out all the options.

As my situation involved a tragic loss, the advocate managed the matter sensitively and was careful to coordinate updates so that I was not forced to suddenly relive events at an inopportune time. During meetings with the providers, they managed the difficult balancing act of keeping out of the way yet providing support and stepping in as needed - always a reassuring presence. Their patience and persistence ensured that actions were followed up, even when providers were unresponsive at first.

Finally, when working with the advocate, they took a personal interest in me and my family. This helped enormously in building trust, something I must admit to having taken for granted until reflecting on it. I am very grateful to the advocate and the team at Healthwatch for helping us to reach a positive outcome.