Oxford University Hospitals NHS Foundation Trust

Supporting OUH Staff after the Death of a Child

In the Immediate Aftermath of the Death of a Child

The death of a child is devastating and may have been completely unexpected. Such grief may be unimaginable to those who have not experienced it.

Everyone deals with death and grief differently, and each member of staff's needs will be different. However there are some common themes which come up regularly with bereaved parents, including those who work in health care.

Acknowledge the death of the baby/child. Ask the baby's name and use it. Ask if they would like to talk about their baby and their experiences. You may wish to send a card or note from the wider team. Some colleagues may be invited to or wish to attend the funeral.

Many people worry about saying "the wrong thing". Although no one can take away the parents' grief, simple acknowledgment of the death may make them feel less isolated. Listening to parents' grief and anguish and simply being human and caring can make a huge difference.

Be aware that there are many "types" of loss – miscarriage, stillbirth, neonatal death, termination for medical reasons, sudden infant death, and death of an older child. These distinctions may be treated differently from a legal perspective. However grief cannot be ranked or measured. The death of a baby or child at any age is a major bereavement; although the intensity of grief may fade over time and they are likely over time to live with their loss in a "new normal", they are likely to grieve for a long time.

Entitlements and Benefits

Entitlements and benefits are complicated and depend on a number of factors including length of service and the age or gestation of the child. Issues around being given the wrong information about entitlements can compound grief:

"Our little girl was born bang on 24 weeks... I had to fight for my maternity leave. My employer and the first BMA advisor I spoke to both misinterpreted the guidelines... sadly I had to go through the long process of speaking to Sands, HMRC, BMA etc to finally get the right outcome and would hate for others to have to do the same."

If the baby was born dead before 24 completed weeks of pregnancy:

From a legal perspective if the baby has died before 24 completed weeks of pregnancy this is termed a miscarriage. Women are entitled to Sick Leave; this will be discussed and confirmed with the GP. Some women can find this very difficult; the grief and shock of a baby dying at any stage in pregnancy (including termination for medical reasons) can be much the same as following the death of an older child.

https://www.sands.org.uk/sites/default/files/SANDS-INFO-EMPLOYERS.pdf

If the baby was born dead after 24 completed weeks of pregnancy OR if the baby was born alive at any stage of pregnancy and then died:

Parents are entitled to paid maternity leave, paternity leave and/or shared parental leave just as they would if the baby had survived. This includes parents who are already on parental leave at the time of the baby's death (for example, after neonatal death or SIDS). It is helpful for line managers to advocate for this and ensure that staff are under no pressure to return to work.

https://www.gov.uk/maternity-pay-leave/eligibility

If the child who has died was older:

Parents have the right to take 2 weeks of **Parental Bereavement Leave** if they're an employee and their child dies under the age of 18 or is stillborn after 24 weeks of pregnancy (**Jack's Law** – see https://www.gov.uk/parental-bereavement-pay-leave)

For other Special leave issues, including compassionate leave please see: file:///C:/Users/twice/Downloads/Special%20Leave%20Procedure%20v4.pdf

While the Staff Member is Off Work

It can be useful to have a trusted nominated advocate for the staff member; this may be the line manager or someone s/he trusts to communicate back to the line manager. Regular but unobtrusive contact is often helpful.

Discuss with the person what they want other staff and colleagues to know and if they would prefer for staff to be told, and if so, what.

"My head of service contacted me to check in. Just for support and nothing more. She was human and managed a sobbing me in her car."

"The biggest thing the partners did for me was just being kind caring humans. Saying kind words at the time of diagnosis, sending thoughtful messages at the time of death and coming to the funeral."

"Consultant keeping in touch, not loads, just to check in and make me aware that I'd be welcomed back whenever was right for me."

"My TPD met me for coffee outside of the hospital. She was so kind, asking about my daughter. She reassured me that work would be there if or when I wanted to go back, and that there was no pressure to return."

"I wasn't entitled to maternity leave and so was off sick. I had emails from medical staffing asking why I was off for such a long time without good reason... I had a phone call from my TPD to ask me what placement I wanted a few days before the funeral... was surprised when I cried on the phone.... My rotation had ended and I wasn't ready to return to training I was simply "let off." So I had no baby, no job and no income."

Supporting a Return to Work

"Returning to work after the death of my daughter was the hardest thing I did. I found it difficult even to go into the hospital building – I walked past the maternity unit where she died, I walked past the bereavement offices. I even found it difficult having normal conversations to begin with."

Healthcare staff are likely to need a very individualised plan for supporting their return to work after the death of a child.

Issues which line managers and other colleagues may be to be aware of, and support, include:

- Tiredness and exhaustion
- Word finding difficulties
- Difficulties with concentration
- Decline in practical skills
- Lack of confidence and self esteem
- Feeling of vulnerability
- Frequent "triggers" of the health care environment.

Some things which others have found useful, and may be offered as part of a plan, include:

- Early referral to occupational health, who can help facilitate a phased return to work, if felt appropriate;
- Supernumerary working if possible to begin with;
- Offer of non-clinical working options to enable the staff member to simply get used to being in a healthcare workplace; this may include for example attending teaching sessions, or doing audit.
- Flexibility around working hours where possible, for example ensuring that first shifts are daytime shifts with appropriate supervision;
- Offer of additional training in a safe environment to regain confidence in practical skills;
- An advocate for the staff member, who can liaise with, for example HR, payroll, clinical and educational supervisors;
- It might be helpful to discuss how employees might manage difficult moments in the workplace, when they may need to take some time out.
- It can be helpful to discuss very small, achievable goals for the staff member; coaching can help with this.

"My educational supervisor took me for a coffee, and I kept crying. I think many people were surprised at how sad and fragile I still was, a year after her death. I had a phased return, which was helpful as I was so exhausted. My coach helped me make small goals, like "take some blood, put in a cannula, talk to a patient." They felt insurmountable to begin with but each small goal added up."

Many bereaved parents have had difficulties with HR and payroll issues (including pay being wrong, or not being paid at all). Returning staff are vulnerable and may not have the capacity to deal with these issues on top of returning. It is extremely helpful for staff to have an advocate to help sort out these practical issues:

"My head of service ensured that HR were aware and helped support the sick pay cock-ups that I encountered."

"Consultant just sorted payroll so I didn't have to worry."

"I was on a locum contract. My boss organised extension to take away the anxiety of contract end looming. I also had to postpone substantive interview twice!"

Specific Issues of Returning to work in healthcare

Returning to work in a health care environment may be highly triggering for health care staff. Particularly triggering areas include paediatrics, neonates, obstetrics and gynaecology and ED.

Other triggers may include seeing pregnant women, babies, and children (especially those of a similar age to the baby/child who died, or who share birthdays or due dates). Caring for others in a similar situation may bring up many complex emotions.

Resuscitation situations and breaking bad news can be particularly challenging and should be supported by senior colleagues.

Seemingly simple questions like "how many children do you have?" can be difficult to answer; bereaved parents do not want to upset the questioner but do not want to deny the existence of their child. It can be useful for bereaved parents to have a planned answer prepared for this question.

Triggers may be totally unexpected, and waves of grief may be triggered for no apparent reason.

"My first session back was in a room with the midwife working next door and all I could hear was the fetal heart Doppler."

"Still feeling very traumatised by going back to the place we had our worse news – will be working on ward next door to the obstetric scanning area."

"What was planned was a couple of easy reviews and an afternoon sorting out admin. What happened was a few people called in sick and I ended up looking after four ventilated babies."

"I looked after a baby whose mother had also had a stillbirth. I was really upset that no one had told me and I read it in the baby's notes as we were seeing the patient. I also looked after a baby who had been incredibly sick; she was now getting better and I found myself jealous that her mother had difficulties breastfeeding, when I never had that opportunity. I had the self-awareness to realise that was my issue and not the mother's, but I found it tricky at the time."

Suggested Sources of Support and Referrals

Resources Specific to Child and Baby Death

Sands (Stillbirth and Neonatal Death charity) - https://www.sands.org.uk/

Child Bereavement UK - https://www.childbereavementuk.org/

Winston's Wish - https://www.winstonswish.org/

The Lullaby Trust - https://www.lullabytrust.org.uk/

Antenatal Results and Choices - https://www.arc-uk.org/

Tommy's – <u>www.tommys.org</u>

SeeSaw (support for families and siblings in Oxfordshire) - <u>www.seesaw.org.uk</u>

Resources Available to all Staff

Employee Assistance Programme – Care First – <u>https://carefirst-lifestyle.co.uk/</u> Username: ouh Password: employee

OUH Occupational Health – <u>occupationalHealthJR@ouh.nhs.uk</u>

OUH Psychological Medicine Support can be accessed via occupational health.

OUH Chaplaincy Team - <u>chaplains@ouh.nhs.uk</u> Lead Chaplain - <u>Sarah.Sewell@ouh.nhs.uk</u> Phone **07552 262 944**

Cruse bereavement Support - https://www.cruse.org.uk/

Resources for Nursing and Midwifery Staff

https://www.rcn.org.uk/get-help/member-support-services/counselling-service

https://www.rcn.org.uk/clinical-topics/end-of-life-care/bereavement

Resources Specifically for Doctors

Practitioner Health Programme - <u>https://www.practitionerhealth.nhs.uk/</u>Practitioner Health is a free, confidential NHS primary care mental health and addiction service with expertise in treating healthcare professionals.

Professional Support and Wellbeing Service - <u>https://thamesvalley.hee.nhs.uk/resources-</u> <u>information/professional-support-wellbeing/</u> Free at the point or use for trainee doctors. Offering a range of coaching and wellbeing services to support return to training (working closely with the local SuppoRTT team) and explore career development, which may be especially relevant after lifechanging personal experiences.

<u>Medic Support Confidential Psychological Support Service for Trainee Doctors - see their leaflet</u> <u>medic-support-leaflet-2019.pdf (hee.nhs.uk) –</u> trainee doctors can access this service for confidential psychology sessions focussed on work-related stress, anxiety or depression, even if they are currently not at work.

Supported Return to Training (SuppoRTT) – This applies to junior doctors in a training programme. Health Education England is committed to supporting trainees to return to training after a period of extended absence (3 months or longer). The supported Return to Training (SuppoRTT) initiative aims to support trainees with their confidence, skills and knowledge so that they can safely and confidently return to practice within their training programme. Trainees absent for less than 3 months may also opt in to the programme.

In order to provide more support to returning trainees, HEETV are offering all returnees three 'reorientation' days, allowing trainees to be supernumerary, with no nights or on-calls, for their first three full days while they readjust to being back in a training/working environment. This period could include activities such as shadowing a colleague; attending departmental meetings; familiarising themselves with departmental processes/protocols. We are aware the experiences and needs of each individual vary, and so if your feel that three days is not sufficient, please discuss this with your ES during your pre-return interview. Full information about this as well as all the relevant paperwork, courses on offer etc are available on the deanery website:

https://thamesvalley.hee.nhs.uk/resources-information/trainee-information/supported-return-totraining/

The OUH trust champion is Sarah Millette, a Consultant Geriatrician, and she is happy to be contacted about any issues related to returning trainees. <u>Sarah.millette@ouh.nhs.uk</u>"SuppoRRT have been amazing with accessing funding for supernumerary posts, courses and advocacy on my behalf for various rota and placement issues. They were also very good pastoral support".

Bereaved Physicians Mums Facebook group – doctors can be directed to <u>shona.johnston@ouh.nhs.uk</u> who is an admin for this group.

Subsequent Pregnancies

Pregnancy after loss can be extremely challenging. This is a time when support may need to be increased. It is not helpful to be overly optimistic about the outcome of the pregnancy; bereaved mothers tend to take pregnancy one day at a time. Bereaved mothers will need a pregnancy risk assessment as per usual. Discuss what will be most helpful.

"The other thing that made a big difference was in subsequent pregnancies I felt very supported both by my trusts and the deanery, fully supported to stop on calls immediately, no questions asked and both asked if there was anything else they could do to help me... they made a big difference to me and how I was able to cope."

"My colleagues sent me away on the days of my scans – they could tell I was extremely anxious and my mind wasn't at work."

Longer Term

The intensity of loss tends to get less over a period of time; bereaved parents remain at risk of prolonged grief, anxiety and depression for many years.

Remember that birthdays and anniversaries can produce new waves of grief; where possible grant leave requests for these special days.

"Birthdays and anniversaries are the worst. Understand that just because I was ok last week doesn't mean I'm ok this week.... Other people remembering anniversaries helps. Very few do but its always made me feel less alone."

"Returning to work was the hardest thing I did. Ultimately I'm glad I did and it was good for me, and helped me to "move forward" in my grief (I don't like the term "move on" because she is always my daughter). It took a long time to build up my confidence at work. My experiences changed me – I was a good doctor before – but I am now better able to listen and empathise. I know what it feels like to be given devastating news. I've never said "don't worry" to a patient again."

Support for Colleagues' Wellbeing

Be aware that line managers and other colleagues may also be deeply affected by the child or baby's death; take the time to talk and offer support and signpost to organisations as needed.

Things that can be helpful to say

"I'm so sorry that {insert child's name} died; would you like to talk about him/her?"

"I'm so sorry, I don't know what to say."

"What would you find helpful?"

"TPD was absolutely fantastic. Listened to me at many meetings and referred me to occ health when I said things were ok as he knew ok was code for actually really bad. Gave me space to talk."

Things that are not helpful

"At least" statements ("at least you can get pregnant, at least you have older children").

"S/he's in a better place now" – any statements related to religious beliefs are best avoided unless you are absolutely sure of the staff member's beliefs.

"Toxic optimism is not helpful. Telling me "oh well, just try again" is in no way helpful. And just makes me feel like I don't have a right to grieve for the child I lost".

"Lots of people at work ask me if I'm going to have another baby after they hear what happened to me. Each time I'm gobsmacked that they've asked. So intrusive. I would advise people to speak in a way that lets others volunteer information but not to probe. I think that because health care professionals have such personal conversations with patients, they can forget the normal boundaries with colleagues and friends."

With many thanks to the wonderful ladies on the Bereaved Physicians Mums Facebook Group for their contributions (given with consent) to this guidance.