

Most Powerful Round “Great Expectations” Hinchingsbrooke Hospital

We have held Schwartz Rounds at Hinchingsbrooke since April 2016. We are a small hospital and our audiences at rounds average around twenty. We'd like more, but the smaller group does mean that people are prepared to say things that they might not share with a larger audience. We get people from many different departments, both clinical and non-clinical. We've therefore gone for a wide range of topics, for example “Brexit and our staff”, “Right to strike?” (during the junior doctors' strike 2016) and “Back to work after mental illness”. For our September 2019 round the steering group chose the title “Great Expectations” to reflect the gap between what patients and families expect and the reality of 21st century illness. Here is our first panellist, Carly McDonald, Bereavement Midwife's account.

Pregnancy Loss: From Great Expectations to Heartbreak

“For couples who have never experienced pregnancy loss the vast majority never even consider the possibility of miscarriage, stillbirth or neonatal death. They naturally assume that a healthy baby will be born and if born poorly, that modern medicine will ensure that their baby survives. There is a belief that by ‘doing all the right things’ during pregnancy, a well baby is guaranteed. Indeed, many couples suffering the loss of their child will admit to having been naive previously.

From the moment a woman has a positive pregnancy test, which is often very early on she starts to bond with her baby and think about the reality of parenthood. Throughout this bonding process, parents visualise their future. They look forward to special ‘firsts’, such as first smiles, first steps, first words.

Parents-to-be arrive for their antenatal appointments and scans feeling excited at the prospect of hearing their baby's heart beat, seeing how much their baby's little fingers and toes have grown.

Therefore, the utter horror that parents feel when they discover there isn't a heartbeat, or when they start bleeding or an anomaly is diagnosed halfway through their pregnancy, is hard to put into words. Nothing can describe those feelings of loss. From great expectations, to heartbreak.

One woman described it as ‘the bottom falling out of her world, a pain that she never believed she could feel, so deep, so dark, so traumatic’.

All those thoughts of baby shopping, starting to pick out names, wondering what the baby would look like, what changes they would need to make as their family grew, instantly become unimportant and are often replaced with thoughts like ‘what is happening’, ‘why is my body betraying me’, ‘what was I or we doing wrong’, ‘what are we going to tell people’, ‘what are they going to think’, ‘why did this happen’, ‘I hope they don't ask me questions’, ‘what happens next’.

When a baby dies, parents never get the chance to know their baby in the way that we normally think of knowing someone. Their hopes and dreams for their child have already become a part of their life and so they have not only lost a child, they have lost the chance to see their baby grow, become a part of their family and realise his or her potential. A loss of hopes and dreams. A denial of part of their future, part of themselves.

From great expectations, to heartbreak.

The death of a baby defies the natural order of life. Children are not supposed to die before their parents. While the death of a parent or friend represents a loss of your past, when a baby dies families lose a part of their future. Parents grieve not only for their baby, but for their parenthood.

I have been supporting women and families who find themselves in this devastating position throughout my midwifery career. However, in the last year since being appointed as the bereavement midwife it has become my primary focus.

For many women, sadness is the most heart-wrenching emotion and one that consumes them. Indeed they must feel it, face it and embrace it, as part of the grief journey. I believe that it's important to reassure women that this feeling of sadness or grief may always be a part of them, but not as intense as time goes on.

Denial, anger, guilt and jealousy are other emotions that bereaved parents describe. They may be tormented by 'what ifs' and 'if onlys'. They will never 'come to terms' with their loss, they will never 'move on', but instead learn to move forward. They may never feel 'back to normal', but instead find a new normal. This experience will change them forever.

Families must be encouraged to grieve as a way of giving meaning and purpose to their loss. Each individual grieves differently, there is no right or wrong way and no time limit. It is impossible to predict how a bereaved parent will feel from day to day, or hour to hour. Indeed, I often advise bereaved parents that their grief is unlikely to pass through distinct emotional stages and to think of the grieving process as a more fluid experience of a variety of emotions.

In our society, death is not talked about freely. The death of a baby is even more hidden as it violates expectations. Therefore, some people do not know what to say to bereaved parents or what to do to help them. Sometimes not saying anything and just being present is all the person needs at that time. Acknowledging the depth of the loss to the parents is paramount.

Some bereaved families want as much information and detail as possible, others prefer less as a way of managing stress and anxiety. It's important to pick up on parents' cues in order to help guide this process.

Some parents need to keep busy and occupied whereas others need quiet. Enabling couples to find a balance is important.

Bereaved parents feel the pain of loss. The pain of what might have been. The pain of the dreams that were shattered but not forgotten.

From great expectations, to heartbreak.

I would like to finish by sharing a poem with you, written and read by David Monteith, a bereaved father of Grace and founder of Grace in Action. I have listened to this numerous times and its impact is always so powerful.

Thank you for listening. "

Video: "I pause" by David Monteith

Carly then showed a video of David Monteith's intensely moving rap about the still birth of his baby daughter, Grace. (This link should get it <https://www.youtube.com/watch?v=dFD7mqgkPRE>.)

Alternatively <http://graceinaction.org.uk/> and clicking on latest videos bottom left, "I pause" should reach it.)

Great expectations of a colorectal surgeon

Our second panellist, David Mitchell is a colorectal surgeon.

“I want to present two cases of patients whom I looked after and performed similar surgeries for. Both were major laparotomies for older patients with cancer.

The presentation and outcomes for the patients were arguably very similar but the expectations, communication and human interactions were markedly different and this left a lasting impression on me.

The first case was a female patient in her 70's who presented with abdominal pain after a CT colonography scan was attempted to investigate bowel and abdominal symptoms. It was discovered that she likely had metastatic (non curable) ovarian cancer and was admitted to hospital under my care for further investigation and treatment. Initially it was planned for an USS guided omental biopsy to confirm the diagnosis and start palliative chemotherapy. Unfortunately there was a delay in getting this test done and in that time a bowel obstruction developed. I was informed of this deterioration on a day when I wasn't in the hospital nor on call but made arrangements to attend to the patient and ultimately perform a laparotomy operation that night with biopsy and formation of defunctioning ileostomy. This proved to be successful in terms of relief of obstruction and symptoms relating to that as well as getting the all important tissue for diagnosis. It was a very challenging operation due to the extent of the disease.

It was a major decision to take her to theatre and the operation revealed high volume abdominal disease. I felt I had done my best for her and 'gone the extra mile' both in terms of performing the surgery myself and also giving her the benefit of the doubt as to whether surgery would help. The alternative treatment plan for such a patient would have been palliative care and discussions about preferred place of care and dying.

She made a slow but steady recovery and it became clear that she would become well enough to receive chemotherapy as per her wishes. This was to be coordinated via the gynaecology MDT.

Following on from this the patients' son informed me of his wish for his mother's care to be transferred to the Birmingham area close to where he lived. I never personally met with him and we communicated on the telephone. Such a transfer as an inpatient proved impossible to negotiate despite my efforts and the patient was ultimately discharged from Hinchbrook to a care home near her son.

The subsequent referral from our gynaecology MDT to oncology in Birmingham did not happen smoothly although by this stage I was not directly involved in this aspect.

I felt I had met expectations for my patient. She had life-saving/prolonging surgery and diligent post-operative care. She was safely discharged from hospital and was well enough to receive chemotherapy treatment that would prolong her life.

The second case was another patient in his 70's who was referred to me from the medical team who had been treating him for a liver abscess. During investigation with CT scan it was felt he may have a mass in his transverse colon which could be bowel cancer and which in turn could have caused the abscess (bacteria travelling from the bowel to the liver via the portal circulation). When I first met the patient he was clinically improving with the antibiotic treatment and the advice from myself and the colorectal MDT was for an outpatient colonoscopy and biopsy to be done to confirm the diagnosis with a view to hemicolectomy surgery once he was well enough.

Similarly to the first case he developed a bowel obstruction whilst awaiting discharge and was managed by one of the other surgeons (over a weekend) conservatively using nasogastric tube to decompress the bowel. Unfortunately when I next came to review the patient he had developed peritonitis consistent with bowel perforation. He was in a lot of pain despite morphine. I had a very frank discussion with the patient and his two sons who had both been present during their dad's hospital admission. I had met them all on numerous occasions and so we were familiar with each other and what the likely diagnosis was.

We agreed to proceed with laparotomy surgery with the hope of resecting the mass and the perforation. This was not possible as the mass was in fact densely adherent to the liver and therefore 'inoperable'. I was able to control the perforation with a caecostomy tube, create an ileostomy and then washout the abdomen. This surgery confirmed that the diagnosis was advanced bowel cancer and it in fact provided excellent palliation from the abdominal pain. Sadly however the patient died a few days later whilst receiving palliative care support.

Reflections

For the first patient she survived the surgery and was still alive about 1 year afterwards having been given chemotherapy. The hospital received a written complaint from the son about the delay in getting the omental biopsy and the difficulties with the transfer of care to Birmingham.

For the second patient he died shortly after surgery. His two sons arranged for the collection from their dad's funeral to be donated to the hospital. They were overwhelmed by the quality of care their dad received and they took great comfort from knowing that the cancer was 'inoperable' from the start and therefore nothing more could have been done. This was another unexpected benefit from performing the surgery.

I hope it is clear that there are many expectations that can be addressed by hearing about these two cases. As a surgeon I thought I had done 'a good job' in both cases but was perhaps more pleased with the outcome for the first patient than the second. It was therefore a shock which saddened me to receive the complaint. The hospital donation on the other hand gave me great comfort. One might have thought it would be the other way round?

Both surgeries were ultimately palliative procedures however the first case this was expected and the second case it was only realised once surgery had been done. It is difficult to be sure how this influences expectations.

The family response was so different in these similar circumstances. I do wonder if things may have been better for the first family had we been able to meet face to face rather than on the phone. This certainly proved to be successful for the second patients' family.

Most importantly the patients had expectations. I think the female patient was still hopeful that chemotherapy would somehow provide a 'cure' for her even though this was not how the information was presented. The second patient was much more focused on his symptoms and quality of life rather than prognosis or length of life. One can only wonder if these expectations influenced how each patient recovered and how long they survived."

Impact

The impact of Carly's account and David Monteith's rap video was immediate. We are unaware of any other Schwartz Rounds showing a rap! Our second speaker, David Mitchell a colorectal surgeon said, "I wish I'd watched that video before I spoke." In fact the impact really happened before the round even started: our audience that day was over forty, double the usual size. In the discussion afterwards people in the audience said things that they'd never shared before, feeling in a safe environment. Medical members of the audience were all too familiar with David's experience of getting complaints when they felt they had done their best.

The mood of the Round was best summed up in the feedback comment "Excellent and very moving." Since then we have had regular nurse/midwife representations at our rounds adding to the mix of people and professions that benefit from them.