

Millions of women, mostly in Africa, experience appalling suffering and shame due to a devastating but preventable medical condition / By SARAH MAC DONALD

'The worst thing that can happen'

IN THE BESTSELLING novel *Cutting for Stone* Abraham Verghese writes about a woman living with obstetric fistula who is shunned by family and community: "The world was lost to her and she to it..." One of the story's main characters, Shiva, is a surgeon who becomes adept at repairing the condition, which occurs after a prolonged or obstructed labour, causing a hole to develop between the woman's birth canal and her urinary tract and/or rectum. The physical injury results in urinal and sometimes also faecal incontinence as well as infection.

The majority of those afflicted are young girls. They endure a lifetime of reproductive health issues as well as social ostracism because of the smell associated with their incontinence. Pulitzer Prize-winning journalist Nicholas D. Kristof describes sufferers as "trickling bodily wastes and shunned by everyone around her". Obstetric fistula is, he writes, "just about the worst thing that can happen to a woman".

Shane Duffy is a consultant obstetrician and gynaecologist at Chelsea and Westminster Hospital, London, whose expertise is antenatal and postnatal care, including perineal trauma and female pelvic floor reconstruction surgery. He is also a volunteer fistula surgeon at Kitovu Hospital in Uganda, where for more than two decades he and his team have provided surgery to patients with obstetric fistula.

As part of a campaign, SafeBirth4All, which was launched in Dublin in May, Duffy spoke at a webinar hosted by the Association of Leaders of Missionaries and Religious of Ireland (AMRI) and the Africa Europe Faith and Justice Network (AEFJN). Religious congregations working in impoverished rural settings in Africa and Asia have been trying to highlight this challenge for women's reproductive health for decades.

THE MEDICAL Missionaries of Mary (MMMs) are among the founding members of the coalition behind SafeBirth4All. MMM sisters have been pioneers in repairing and rehabilitating women and girls living with obstetric fistula in Africa. At the launch, Sr Ursula Sharpe, the MMMs' congregational leader, recalled how more than 40 years ago Sr Anne Ward developed a simplified surgical approach to fistula as well as pre-op and post-op care. Sr Anne treated more than 2,000 fistula cases and carried out more than 3,000 surgeries, while another MMM, Sr Maura Lynch, was involved in 1,300 operations. As a spokesperson for the MMMs told me: "We are just so tired of seeing millions of women suffer needlessly."

The Geneva-based Spiritan priest Fr Edward Flynn first came across obstetric fistula when he was a missionary in Pakistan in the 1970s

and 1980s. "Obstetric fistula is preventable," he says. When there is better education for women and girls, the age of first pregnancy is delayed. Timely access to obstetric care, including caesarean section and/or catheterisation if a woman has an obstructed labour, will also prevent the development of what is a devastating condition if left untreated.

The campaign aims to bring an end to this unnecessary "suffering and torture", Dr Toni Pyke, AMRI's Justice, Peace and Ecology coordinator, says. Most of the women affected are poor and live in rural areas, and are "dependent on their families and their elders; traditional structures dictate their reality. They are in many ways unseen and unheard."

"Pregnancy is an unpredictable journey," Duffy acknowledges. "The time of greatest risk tends to be during birth. Unfortunately, the risk of death during childbirth is very high in sub-Saharan Africa, while there is also significant risk in parts of Asia." A 2012 study showed the incidence of fistula as nine per 100,000 live births. "It is quite

a prevalent thing and untreated fistula can leave victims leaking uncontrollably." According to Duffy, there are two million women globally needing repair surgery for fistula, but only 15,000 have surgery each year. The cost of fistula repair for a single patient is between \$100 and \$400 – "not an awful lot" of money for a surgical operation, though as Duffy points out, it would mean "a lot for the patients who are experiencing it". He and his team have tried to improve care in a small area in Uganda by developing patient pathways, education and social reintegration programmes. "A paradigm shift is needed in obstetric fistula management. Since 2004 we have repaired over 9,000 fistulas and we have trained 44 local Ugandan surgeons."

Repairing the physical damage is one thing, but patients also need psychological, physical and spiritual health care. Sufferers are ostracised. They are ridiculed and unable to earn a living. They cannot go to church, they cannot even attend weddings or funerals. More often than not they are neglected or abandoned by their husband and family. They become the poorest of the poor.

Harriet Nabatte, a fistula patient at Kitovu Hospital in Uganda, was interviewed for a video for the SafeBirth4All campaign. "I pushed for a long time – about nine hours," she recalls. "The nurse was telling me, 'Push, push...' I pushed for very long. After that the urine started dropping and dropping. The

doctor checked me and told me, 'You have a problem with fistula.' He told me to go to Kitovu Hospital – 'They will help you.'"

FOR DR PYKE the fact that women and girls continue to be at risk of obstetric fistula is "a shocking failure", a denial of women's right to good maternal care and human dignity. "The impact of obstetric fistula on women is traumatising. Not only is it a physical injury with many years of persistent incontinence and other medical complications such as prolonged infection but most often the baby is stillborn and in some cases the women become infertile. In countries like Angola, where motherhood is key to a woman's social significance in her family and her community – this can be devastating."

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Last January, Dr Pyke, Fr Flynn and Irene Carson, a midwife for many years in the NHS in the UK, travelled to Angola to learn first hand about the reality for women who are living with obstetric fistula and to see what prevention measures are being taken. "We met surgeons who

perform fistula repair surgeries and we spent time in hospitals that had the necessary expertise to carry out fistula repairs," Pyke told me. "We heard stories of women who had or were living with fistula, some for more than 40 years, and others who had had many surgeries with only limited success. We listened to stories of abandonment, stories of joy, stories of the psychological legacy of living with the social stigma that resides alongside the injury."

Votoka, a local NGO in Angola meaning "rise up", trains nurses and health staff to understand the causes of obstetric fistula, how it should be treated and how it can be prevented. It also organises care for patients before and after surgery. Advocates committed to the prevention of obstetric fistula work through local ambassadors like Makalino, whose wife Lorinda is herself a fistula survivor. The ambassadors try to raise awareness on the ground about prevention and how the injury need not be a life sentence. Votoka organises at least four surgery campaigns a year. But with 20,000 women estimated to be living with fistula throughout Angola, 1,500 new cases every year, and the capacity for fistula repair at around 600 per year, "this doesn't remotely address the need on the ground," according to Toni Pyke. "Prevention," she says, "really is the key."

Sarah Mac Donald is The Tablet's Ireland correspondent.