Silent suffering

Jill Emery

I would like to share with you my feelings on what it is like not to be able to have a child of our own. For years I was told to use contraception to prevent a pregnancy and idly went on taking the contraceptive pill until the time came for us to try for a baby. We had never really thought about having difficulties conceiving and it all came as a bit of a shock when we realised that there may be something wrong.

Infertility manifests itself in many ways. Christmas is perceived as being a family occasion, but for me, and for many infertile couples this is the worst time of the year. I see family and friends going off to watch nativity plays and I long to be there, sitting in the audience, shedding a tear when I see our child walk on the stage.

We face pain and heartbreak when friends and family have babies. We cannot avoid the situation but desperately wish that we did not have to see the new arrival. My sister in law recently gave birth to a baby girl. The baby was thrust into my arms and the feelings I had were ones of mixed emotion. She stared up at me and I had feelings of both joy and great sadness. Joy because all new life is a miracle but sadness as I so wanted that baby to be mine. The pain became even greater when the baby was given to my husband—I saw him holding the baby and felt that he was deprived of so much because I cannot give him his own baby. We will never hear our children's first words nor watch them take

their first steps. The saddest part will always be not hearing a child call us Mummy or Daddy.

As infertile couples we shed many tears, sometimes openly but often in private when our lives seem so desolate. We feel that no one understands our grief and sorrow, and that we are the only ones in the world with a problem. After years of treatment we know that is not the case, but infertility makes you feel as if your world has come to an end and no one else can possibly share the same grief as you.

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Our families and friends try to understand but often make comments that dig deep into our souls. They refer to our successful careers, our new cars, and exotic holidays. We would swap all the material things in life for a baby, but if we cannot have a baby then we must try and make the best of our lives and endeavour to fill the gap that childlessness leaves.

My mother has always told me how much joy I have brought to her life. She was 40 when I was born after she had been told that she would probably never have a child. That was 33 years ago when infertility was practically unheard of. But the stigma of infertility is still as prevalent now as it was then. Couples do not want to tell their families and friends of their problems as it is still perceived as being something that should be kept quiet.

Fatherhood and manhood have been linked through the centuries and this has created a culture where to have no children means you are not "much of a man." We have all been subjected to comments from male friends such as "I will give you a baby" or "I only need to look at a woman and she's pregnant." How callous these comments are. Is it any wonder that the stigma of infertility exists?

Men's emotional needs are neglected so often during the investigations and treatments. Men have been conditioned to be brave and show no emotion and many men feel torn apart by infertility but feel they cannot show it. Men hear their family, friends, and colleagues wistfully sharing the delights of being present at one of the most moving moments in anyone's life—the birth of their child. Imagine how that must make a man who knows he will probably never experience that miracle feel.

Infertility is like a bereavement as we grieve in the same way. The difference is that our loss is not something tangible. We cannot look back on times we have shared with a loved one as we do with a normal bereavement. We can only look back on an emptiness and years of pain and desolation. Our only consolation is to look forward with hope. Assisted conception is our only hope.

But why do we have to fight in vain for the family we want? Why is in vitro fertilisation the only treatment excluded in the patient's charter on waiting list limits? For most couples it is an option only if you can pay. Who has decided that the pain we suffer is of no concern to the NHS?—JILL EMERY lives in Ashington, Northumberland

Was it wrong to want a baby?

Alison Cobb

Some months ago we failed in our fourth and last attempt to have a child using ovum donation and in vitro fertilisation. I am 61. With my first husband, in my late 20s, I had had three children in four years. We later separated and then divorced. Twenty years ago, when the youngest was 12, I fell in love with a wonderful man. At 47, he is 14 years younger than me. He has no children.

Unsure that love with such a big age gap could last, it was at least five years before we asked a fertility clinic why I did not get pregnant. We paid for a sperm test and laparoscopy, which indicated nothing wrong except that at 47, I was probably too old. Later that year, accepting that we would never have a child together, we got married

and lived happily in various remote places in Africa.

Eleven years after that, back in England, one of my children, now a doctor and a mother, told us that a woman of 60 in Italy had had a baby. We questioned ourselves all over again. Was I so old now that I could not bring up a baby? Were we selfish? Would it be teased? Would it wish it had never been born? Surely not. I would, I hoped, be there for most of its childhood. My husband, I knew, would be a wonderful father. He was then 44, and many of his contemporaries, our friends, were then and still are fathering children.

After a long search we were thrilled when a famous teaching hospital in this country took us on. The hospital was afraid of the press and asked us to tell no one. It was hard not to talk about it to friends, nor to my husband's loving parents. We felt very isolated.

We were impressed at the excellent treatment, at the kindness and support that we received from the staff, and in particular from our sensitive, calm, and openminded counsellor. We were surprised that our case had to go before an ethics committee though

we ourselves were not allowed to, nor even to know who the members were. Nothing had changed for us: we had always wanted a baby, and now, long after we thought it was too late, there seemed, amazingly, to be a tiny chance. If we succeeded what on earth did the ethics committee think we were going to do with such a hard won baby, if not dearly love it?

We were thoroughly warned of the chances of failure and of the unknown problems due to the lack of experience in treating people my age. But we passed the hurdles and the HIV test, did a drugs dummy run, and received a very funny letter of congratulation on the state of my endometrium.

We were walking on air when the day for treatment came. Progesterone was then administered by pessary, whose only known side effect is euphoria. Wearing bath caps and sockettes made of blue J-cloths, we were given two small jars and shown into an amazing room, brilliantly lit, which boasted posters and magazines of smiling women with huge breasts and no pubic hair, sitting in unfortunate positions. It was an absurd and disgraceful place to make a baby. After

the first try we changed from euphoric pessaries to stabbing alternate buttocks with hefty needles of progesterone in oil; our general practitioner taught my husband to inject me.

Sadly, the first three embryos came to naught, and their frozen siblings later died of being thawed. But we had been promised three attempts, and we were lined up for the next cycle. And then that lucky woman of 59 gave birth to twins at Christmas 1993 and the sky fell in.

In early January our hospital sent us a letter out of the blue saying that it would not treat us any more. We lay in each other's arms and wept. Thank God my husband was not away in Africa: it frightens me to think how I should have coped alone. We begged them to relent, but the media hullabaloo had terrified them, and they refused, even though the clinical circumstances had not changed.

That left Italy. No, not the clinic everyone has heard of. Another. In Italy no one suspected us of any kind of foul play. They did not wish to judge whether my husband should want a baby, nor why I, knowing the risks, should want to try to have it for him. They could make no promises, but they

would try. They charged a lot less than in England, but with travel and hotels it came to about the same. We made three visits.

The clinic was quite old fashioned and dark, but there were no nasty pictures. They showed us the embryos down a microscope, instead of flashing them up on a screen, but

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sadly these too failed to implant, on all three occasions. On advice, we had set ourselves a limit. And that was it.

So how do we feel, now that we know again that my beloved husband, who would have made such a dear father, will never have a child? Well, it is better to have tried and failed than never to have tried at all. We are enormously grateful to all those people who believed we were not wrong to try, and let us do so, and above all to the four anonymous women who donated their eggs.

Was it worth the £12 000? We have spent our savings but can put that right in time. Knowing what we now know, was it worth trying? Yes, absolutely.

But mostly we wonder at the wisdom of all those rules and regulations. When a man fathers a baby in his 60s it is a cause for celebration, and no ethics committees will prevent him. If a woman has one at that age she is disgusting. How, in this age of equal opportunity, does that make moral or legal sense?

The press sometimes implies that the world is in danger of hordes of mad grannies trying to procreate, but it has been left to guess why any granny would want to. Nothing would have made me want another baby, much as I love them, had I still been on my own. But recognition that my husband, like most other men, wanted to be a father, made it seem right to try. Why are the rights of potential fathers not given equal weight in the guidelines of the Human Fertilisation and Embryology Authority?

All that is left to us now is the faint chance of surrogacy. But where in the world will we find a woman so wonderful that she will have a baby for us?—ALISON COBB *lives in Oxfordshire*

Cardiac surgery in the Dunkirk spirit

Tom Treasure

At Dunkirk troops waited on the beaches with no certainty of a place in a ship, and then queued in line out into the sea to cross the Straits of Dover. The craft that took them were overloaded, the crews under pressure, tired, pushing their endurance beyond what was reasonable in any planned operation. But the circumstances were desperate. That rout came to be seen not as the retreat of a defeated army, but as a victory of humanity against the odds. There is something about the practice of cardiac surgery in the health service in Britain in 1995 that reminds me of Dunkirk.

We struggle to stay within the 12 months' waiting time that the patients' charter promises. Each week we fail to make the progress on the waiting lists that we would dearly like because more urgent patients are in the hospital and demand our attention. Elective admissions are cancelled as we struggle to clear the inpatients, waiting like the queue in the water at Dunkirk. In order to cope we fill our intensive care units to capacity, shorten the stay of patients in those beds to the limit, and fast track them through progressive care and recovery facilities. As in wartime, we cut corners, we rediscover the concepts of triage, and we stretch our personnel to the limit. Sometimes important advances are made under such pressure. Human beings may emerge as heroes, but the moral leverage put on our nursing and junior staff to work harder, longer, and nearer the brink of safety is beyond what is a proper duty of respect for the standards of others.

In the main, our patients can see the

pressure that we are under and tolerate the waiting, the disappointment of last minute cancellation, and seem glad to have the opportunity of surgery, as they remind themselves that some others have been less fortunate. That is the Dunkirk spirit. The difference is that the evacuation of Dunkirk was a short term, desperate solution. What I am involved in goes on, and on, and on. Unlike Dunkirk, our patients feel entitled to complain about delays, lack of comfort, and the catering.

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The public is aware of what is available in modern health care. They expect the service to have the capacity to cope, in a reasonable time, with those who turn up suddenly and unexpectedly, and not for them to have to wait, becoming ever more desperate as they do so. Under our present circumstances the whole basis of the relationship between doctor and patient is eroded—the availability of an operating slot dominates everything. Contracts are shifted in job lots of 50 or 100 cases from one district to another. Proper preparation for surgery is disrupted by the chaotic on and off run up to the operation; plans are made to be changed, promises are made only to be broken. The well ordered process of adequate investigation, followed by psychological and emotional preparation for surgery has gone by the board.

The usual response to a complaint such as mine is to diminish it by making it seem an isolated example. At the annual meeting of the Society of Cardiothoracic Surgeons in March 1995, in a session devoted to audit and organisational issues, there were papers from two major regional units, one in the

north and the other in the south of Britain, describing their different systems for prioritising patients sitting in beds, waiting. In one unit 29% of coronary surgery was performed on an urgent basis and in the other 43% of practice was either urgent or emergency and never got on to a formal waiting list. A half of urgent cases in hospital for surgery on that admission waited in the cardiac unit over a week, some up to three weeks, for an urgent operation.

In those units, as in ours, the surgeons are torn between responsibility to the patients on their waiting lists and these other patients waiting in the hospital. We are under pressure from medical colleagues to take patients with repeated episodes of ischaemia, on intravenous infusions of heparin and nitrates, who are teetering on the brink of an infarction, and possibly death, in preference to those we promised to care for months earlier. The mismatch between expectations and the reality of our resources is becoming intolerable. Most of my colleagues seem to be able to keep up the Dunkirk spirit and do not complain much, but I feel battle weary.

What is the solution? We could point at allocation of resources, better organisation of our facilities, a more selective use of the surgery, and so on. All of these are important debates but, in the meantime, I ask us to be honest with each other. Talk of centres of excellence and other forms of self congratulatory cant are irksome.

In our unit we perform 1200 heart operations each year and that volume of work is attained only by considerable effort on the part of the staff of the unit to get as many cases done as possible. It seems to be an impossible struggle. From my perspective it feels like the descriptions of Dunkirk: noble in memory, but grim in reality.—TOM TREASURE *is professor of cardiothoracic surgery in London*