‘The spaceships were cool, too’

Jackie Leach Scully biomedical ethicist

I’m interested in the ways that people and societies work out the morally right and wrong ways to use — or not use — a new life-science development. Over the years, I’ve investigated several different biomedical technologies used by different groups of people. I’m based in the Policy, Ethics, and Life Sciences Research Centre at Newcastle University.

My work is very varied. I do some teaching, but I’m primarily researching at the moment, and when the Faithful Judgements project was running, a day might involve interviewing people in their own homes, or running a dialogue group in somewhere like a cathedral, or someone’s home. Now, I’m analysing data and writing the final report. Some of that is with other members of the research team, and sometimes, yes, just hunched over my computer.

Faithful Judgements is a project looking at whether being a person of faith influences the judgements people make about the ethics of new reproductive and genetic technologies, and the way they make them. In that project, we also explored the personal experiences of Christians and Muslims who had been faced with fertility treatment or genetic testing.

This particular study has its roots in some work I did a few years ago with colleagues at Newcastle and Durham Universities, looking at people’s views on prenatal sex-selection. We noticed that participants with a religious identity sometimes had distinctive viewpoints on bioethical issues, but they were inhibited about speaking about them in public. I wanted to follow that up.

What people are finding in the clinic is that doctors and other health-care professionals steer away from raising questions about faith because of the sensitivities involved (Features, 2 May). If patients raise it themselves, staff find that they can’t answer the questions — which you wouldn’t expect, anyway, because they aren’t religious experts — and they can’t point people to where they should go. It’s not hostility so much as a lack of space for the questions in these settings, and no mechanism for raising the questions as something patients want to discuss.

Faith-group leaders and chaplains, who are, in a sense, the intermediaries, are sometimes very inexperienced in handling the pastoral issues. They may never have had to listen to someone’s dilemmas about genetic testing or infertility. Or they may have met someone having IVF treatment, but the more recent developments, such as egg donation, they won’t have encountered yet.

It’s unfamiliar territory for ministers, and may be unfamiliar for the faith group itself. Some ministers said that, if they asked for guidance themselves, nobody could tell them. It’s all so new. A frequent comment was: “Our faith group needs to get its act together.” The biomedical field moves so quickly that often the Church doesn’t yet have a fully worked-out position, and clergy feel ill-equipped to help. That can mean that people feel effectively abandoned as they make their own difficult decisions.

People want to be accompanied on their journey rather than to be told what the destination should be. Nowadays, the internet is often where people go next for information and contacts rather than to others in their own community. And prayer is important to them, both in discernment, and for support in living with the decision they come to.

I come from a very mixed faith background, and had a religious upbringing that was very catholic. Through my teens I was drawn to the Religious Society of Friends (the Quakers), and I’ve been a member now for 28 years. Two of the core values, or testimonies, of Quakers are truth and equality. I think the testimony to truth drives research, wanting to find out something of the truth about things. The testimony to equality underpins a commitment to working with lay people who are often left out of philosophical debates and policy deliberations.

The funding for the project ended in January; so we’re now focusing on disseminating the findings. The first report should be available on our website later this year, and there’ll be the usual academic papers after that. Our findings suggest that many people who are faced with difficult choices about fertility treatment or genetic testing feel unsupported by their faith community, and unsure of where to go for spiritual advice.

We feel it’s vital to ensure that the results reach the people who can use them, to help improve the support they give, particularly health-care chaplains, faith-group leaders, and clinicians. Better understanding about how people of faith approach these issues will also help with more effective and inclusive public engagement and consultation processes.

When making an ethical decision myself, I generally start by finding out the facts of the matter as far as I can; so I probably behave like a typical academic in my personal decision-making. But I also pay attention to intuition and gut feelings, not holding that they are always right, but believing that they can be pointing towards something I’m aware of at some level but I’m overlooking. When it’s a personal ethical matter, I think I’m very Quaker in laying special emphasis on practices of discernment. Sometimes that will mean the collective discernment of other Friends.

The most important decision I made was probably to leave bench science and move into bioethics. But in reality I don’t think you can see the real consequences of a choice until the end of the story. Apparently insignificant things can end up having massive effects a long way down the line — and sometimes in ways you couldn’t anticipate at all.

I’m an orphan with no siblings; so having been taken up by my partner’s family is very nice.

As a child, I read a lot of science fiction, particularly written by women like Andre Norton, Zenna Henderson, and Ursula Le Guin. It’s only with time that I realise how much their values — being open to difference and alienness, being curious, exploring, staying human however sophisticated the technology — shaped mine. The spaceships were cool, too.

I like to take holidays somewhere with mountains, water, and history, and preferably warm.

My biggest regret is that my current lifestyle means I can’t have a dog.

I’ve been profoundly deaf since childhood; so I only hear things within a select range of frequencies. My favourite sounds include trains going past the bedroom window in the night, and the flying fox fly-past at dusk in Centennial Park, Sydney. My partner’s voice when she comes home.

Because I’ve been deaf for so long, it’s what’s normal for me. I lip-read pretty well, and have the benefit of a very powerful hearing aid in the one ear that works. In large groups of people, it’s more difficult. I’m actually married to a classical musician; so I’m exposed to a wide repertoire of music that I enjoy.

Pretty much everything the current contemptible government has said and done are the things that make me angry.

I’m happiest when everyone I love is well and happy.

I’d welcome the opportunity to help Theresa May experience what it’s like to seek sanctuary in a foreign land and find yourself locked up instead; so I’d choose to be locked in a church for a few hours with her.

Professor Leach Scully was talking to Terence Handley MacMath.

The final report on the project, Faithful Judgements: The role of religion in laypeople’s ethical evaluations of new reproductive and genetic technologies, *will be available later this year. jackie.scully@newcastle.ac.uk*

word from Wormingford

Ronald Blythe discusses immortality over a portion of fish and chips

CHILLY May days. Lilacs cense the mown lawns. Blackbirds do their best. Horses stay still and converse. The church smells nice. I gaze anxiously at the ashes — will they escape the plague? The oaks are in full leaf, and the Stour valley is wondrous to behold.

John and I go to the Thatchers for fish and chips, and to look at the immense view. We discuss the Etruscans to muzak, and the insatiable human need to be immemorially entombed. *The Churchyard Handbook* is not much help in this direction. It is generally believed that we will be remembered for 40 years after we are “gone”. But the car park is full of comings and goings above the Iron Age bones. Fresh hedges are green walls, and Mount Bures’ church spire thrusts into a low sky.

My existence straddles two dioceses: Chelmsford, and St Edmundsbury & Ipswich; but, since I can’t drive, they are as unreachable as Rome for all practical purposes. Friends return from them with tales of wondrous singing and preaching. Long ago, I used to imagine what it must be like to live in a close where every day was a procession.

Down at the farmhouse, life is a procession of a writer and his cat. Today, the pair of us pause at the glorious sight of the vast laburnums in full bloom on the long walk. “Look thy last on all things lovely,” Walter de la Mare said. Not that I feel the approach of Last Things — rather the reverse, but no one should miss May or its flowering shrubs.

I once carried an armful of lilac into my grandmother’s cottage when I was a boy. Pandemonium. “Take them out — take them out!” Then, “Poor child, he doesn’t know any better.” She was a Suffolk countrywoman born in the 1870s, and a lover of evensong, and her existence was rich with superstitions. When she saw television for the first time, she said: “There is something I want to know: can they see us?”

Spring brings her near. It was less securely Christian than the winter, particularly Maytime. But the bumble bee trapped in the window would give her unwanted messages. Now and then, Canon Hughes would sit with her of an afternoon, on his round of old ladies, his Welsh and her Suffolk voices winding in and out for the destined half an hour.

The Blythe graves tumble about in the village churchyard, their stones hardly legible. When I took an American cousin to see them, he was indignant at the wild scene. I explained that this was the wildflower bit of the churchyard, to do with saving the planet, or something. He was not appeased.

He stared at the humps and bumps of his relations, and I remembered a poem by Thomas Hardy, in which a London churchyard was destroyed to make way for a railway terminus. Thus peasant dust from centuries past made way for our relations, and theirs would hold a name briefly — 40 years, maybe — after which the faces of the dead would vanish from memory. The youthful cousin doubted this, too.

But the immortality of certain wildflower sites — bluebells, for instance — is something I cannot doubt or rationalise. The Tudor woman Joanna Sturdy, who cast two of our bells (she took on the business after her husband died), would have seen our Arger Fen bluebells, I am sure. Anyway, the Maytime rite of going to see them is never neglected. There they are, in all their jazzy blueness and multitudinous splendour. Just where they were when we were ten.

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