

by Penny Pullan

Sue is on the electoral roll of her local Anglican church. She used to go along to the short, quiet, midweek communion service, but stopped when she realised it was making her illness worse. Sometimes she needed to spend days in bed to recover from just attending that simple service! You see, Sue has lived with ME (Myalgic Encephalomyelitis) for many years. This is a long-term condition that causes many physical health problems, including extreme tiredness. If you were to glance at Sue, you might think she looks well, but underneath, she is often feeling utterly exhausted and in a lot of pain. Some of that pain is emotional pain about being isolated from her church family now that she is unable to attend services. Sue says: 'I have disappeared' and explains how no one has been in touch with her.

Elaine is a Reader, who stepped up in 2020 during COVID lockdowns to run services and support her congregation through that very challenging time. At least, she did until she caught COVID herself and developed what's known as Long COVID. This is another exhausting but hidden condition with similarities to ME, thought to affect over 2 million people in the UK.^[1] Having supported everyone else, she hoped that her church would rally around her in her own time of need. She had valued and included older people who were housebound, but, it turns out, her church no longer valued her. Bringing home communion to Elaine, a person of working age, wasn't something her church would consider, as elderly housebound people took up all of their capacity. Elaine says: "I've even heard people say that I can't be bothered to try and get to church. There is no understanding about what I'm living with and how it affects me."

Ephraim looks well. He can make it to church services, but finds that his ME makes him much more sensitive to the environment around him. His inclusive church proclaims that 'all are welcome'. They like to use incense in some of their services. Unfortunately, Ephraim can't tolerate this as it makes him feel really poorly for a couple of weeks afterwards. He told the church about this, but several times when he arrived for services, he was met with the smell of incense and couldn't go in. He has since stopped bothering going to church.

Maria is often able to make it to church services. She looks well, despite living with ME. While she enjoyed being part of an online home group during COVID lockdowns, these aren't offered anymore. She describes an expectation of being involved in an in-person house group and other aspects of church. If you don't, people just assume you're lazy and don't want to participate, which couldn't be further from the truth. Maria would love to be well enough to be involved! Rotas are particularly annoying, as Maria can't predict how her condition will play out on any future date, as she has fluctuating symptoms. She tends not to get involved in much in church, as doing things involves going on rotas.

Francesca, a Licensed Lay Minister undergoing chemotherapy treatment for cancer, explained the problem with rotas very clearly: "One time I was due to preach, and at 5:30am that Sunday morning, I was in A&E with an infection. You can't predict that!"

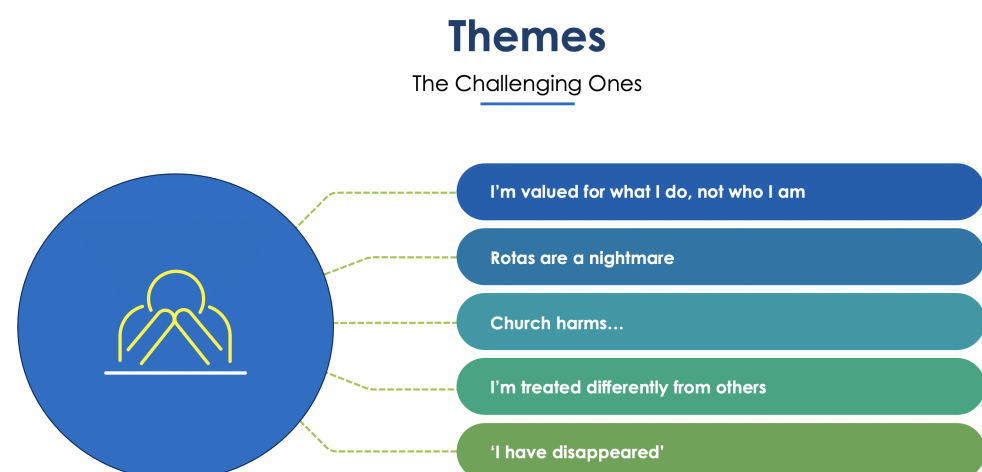
Rotas are different for **Daniel**. As Music Director, he is only on rotas he controls, which means that he can change them if he needs to. At his piano throughout the service, he is able to sit down rather than stand. All of these things, along with a very supportive Rector, means that Daniel

is able to be present at services despite his Long COVID. It's not always easy – the sermons could do with being shorter and more digestible, but he feels included, and a valuable member of his church.

Sarah's church offered her prayers for healing, but, as time went on she remained ill, despite their ongoing prayers. Some people suggested she needed to repent as she wasn't getting better. She found echoes of this in the liturgy, which sometimes conflated health and salvation. The end result was that Sarah started to think that God must hate her, as otherwise he would have healed her. This bad theology ended up isolating Sarah and keeping her away from church when she really needed support and connection. She still lives with hidden illness.

All of these stories, and more, emerged as I explored the inclusion and belonging of people of working age (18-65) in their Church of England communities. This research was a qualitative study last year as part of my MA in Theology, Ministry and Mission.^[2] (Names and stories have been changed or combined to ensure that no individual is identifiable.) When I reached out, 61 people responded by sharing their experiences in a survey. I interviewed 13 of these people in depth. Exploring their stories, many very harrowing to hear, revealed a very mixed picture of churches in England and how they deal with hidden illnesses. I developed eight themes, five of these were challenging and three were positive.

The five challenging themes are:



- **'I'm valued for what I do, not who I am'**—Church culture seems to value productivity over personhood, which doesn't reflect Jesus' example of valuing people for who they truly are.
- **'Rotas are a nightmare'**—Rotas lack flexibility, making it difficult for people with fluctuating health conditions to participate fully in church life.
- **'Church harms...'**—Some participants reported experiencing spiritual, mental and/or physical harm within their church communities due to their invisible illness.
- **'I'm treated differently from others'**—People with unseen illnesses felt they were treated differently from others, particularly those with visible disabilities."
- **'I have disappeared'**—Half of those interviewed said that this statement resonated with them, as they had disappeared from their church

communities due to their invisible illnesses.

The more positive themes were:



- **Online can really help**—Online access to resources, such as streaming services, interactive teaching sessions and membership of small groups, can provide valuable support for those with invisible illnesses.
- **Leadership really matters**—The leader sets the tone, such as allowing people to choose whether to sit or stand. An inclusive tone makes it easier for those with limited energy to participate.
- **The church could be...**—Small changes in church practices could transform church communities into spaces where people with invisible illnesses feel welcome, included and valued.

Why should Christians care about all of this? Studies haven't really considered invisible illnesses in the past.^[3] But we know that every person, with a hidden illness or not, carries the image of God. They matter. In 1 Corinthians 12, Paul uses the idea of the church as the Body of Christ to explain how all church members are meant to be equal, despite our differences. He talks about different organs, eyes, hands and feet, each bringing something unique to the Body. Paul does not suggest the surgical removal of organs that can't pull their weight. Instead, he emphasises that when one member suffers, all suffer together. If we really followed Paul's teaching, the church could be transformed into a place where people with hidden illnesses and chronic conditions always felt welcome, included and valued. Sadly, the 'havoc wreaked by indifference'^[4] continues to leave some excluded and others less valued than they should be.



Model

The Body of Christ
from 1 Corinthians 12



Stop the harm

Physical, mental,
spiritual and
emotional



Rotas

Make rotas flexible
so more can serve.



The Same

Treat people well,
whether they have
cancer or ME.



Explore

What church
could be...



Listen

Listen to people
and their unique
set of needs.

[1] Office for National Statistics, *Self-Reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024* (ONS, April 2024)

[2] Penny Pullan, *'The Ethics of Inclusion: exploring whether people of working age with invisible illnesses and chronic conditions feel they belong in their church communities'* (Unpublished Master's Dissertation, Durham University, 2024) Available from the author by emailing dissertation@makingprojectswork.co.uk or from ethicsofinclusion.study

[3] Naomi Lawson Jacobs and Emily Richardson, *At the Gates: Disability, Justice and the Churches* (DLT, 2022) is an exception, including those with both visible and invisible disabilities

[4] Miroslav Volf, *Exclusion and Embrace: A Theological Exploration of Identity, Otherness and Reconciliation* (Abingdon, 1996) p. 67

About the author

Penny Pullan is a Reader in the Diocese of Leicester, the author of a number of leadership books, teaches leadership for St Hild, and runs her own consultancy. She has cared for a loved one with ME for 35 years, who has sometimes not felt included in church. The next step for her research is exploring the intersection of leadership and invisible disability.

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