

MESSAGE FROM OUR CHAIR

The Long and Winding Road

Firstly, I want to welcome the new clinical pathway from the BPF (*Please see page 22*). I hope we all can get behind this and lobby wherever and whenever possible. We have always needed an holistic and informed polio service and whilst it is still a dream this a step on the way.

That said, implementation is everything and something that sits on a shelf does nothing and I have had plenty of experience of that. Realistically we have an NHS in crisis both in terms of demand, personnel, funding, and infrastructure. Change is something that will take a decade or more to fix, and only then if we all agreed how, and start tomorrow. The reality is that achieving this ideal will be, to quote a Beatles song 'A long and Winding Road'.

Physical and Emotional Pain

I want to focus on one area. That is pain, not just physical but emotional distress and the psychological. It has often occurred to me, both as a polio survivor for 68 years and as a psychologist for over 35, that this is an area where we often find ourselves met with ignorance and a lack of understanding in the face of our, often unusual history and particular life experiences over decades.

Pain is a huge subject area, both complex and highly individual and subjective. Yet we all experience pain throughout our lives from our first breath to our final breath. Indeed, it is part of everyday life. It's normal, and its function is to alert us to threat and protect us from harm. But how we experience it varies and that is true whether it is an emotional trauma, physical injury, or illness or of all of them. It is the interaction that makes it so complex. Ultimately it has such an impact our quality of life, our ability to engage and be our true selves and who we want to be in the world.

From my early childhood polio rehab days to now as I age with PPS, like many of you I'm sure, I have had my fair share of pain, both physical and emotional. I'm not sure the physical pain was the most difficult. Pain that is short term, predictable and understandable is unpleasant, even difficult, but perhaps easier to deal with, than ongoing chronic pain and or emotional distress. Pain isn't just a physical experience, though we may often perceive it to be. But its impact is mediated in the brain by fear, anxiety, memories, social interactions and more. It also differs from person to person; it differs within the same person differently at different times or at different stages of our life and circumstances. The pain when I was having my spinal fusion in the RNOH was often intense, but I was 17, informed and had a long-term relationship and faith in my surgeon. My cognitive view was that this was a gateway to a better future, and indeed less pain. Whether that was objectively true, or my assessment of the risks were over optimistic is by the way, but my psychological approach and belief and sense of control mitigated my fear and experience of the pain. That is a very different situation and situation when having pain at the other end of my life.

The Pain Cocktail

The pain, be it emotional or physical, that most of us meet in our lives is not well served by pharmacological treatments. Most medications or analgesics have unwelcome side effects, whether for mental or physical distress, and on their own often only provide partial help. This is especially true of what's available for chronic pain. Pain is perhaps a kind of cocktail made up of the biological perception of pain in our bodies and the emotional and psychological distress that we experience living in the world and that is 'our' unique and individualised pain cocktail. As disabled people we surely have first-hand experience of what that means.

The Polio Rehab Legacy

My particular interest has always been focussed on how as lifelong disabled people our psychological, emotional and social integration needs are often marginalised, especially as we age. This was no more starkly exposed than during the pandemic and how ironic that is for us as the survivors of the polio pandemic. Part of our 'cocktail' is that back in the day, as polio patients we were indoctrinated into a medical model with an almost unswerving faith that doctors, medical professionals and the NHS were always right and if we pushed ourselves to the limit, we could overcome anything and even 'pass' as non-disabled and be part of the world 'as if' our physical impairments and psychological experiences hadn't happened or were at least invisible or irrelevant to how were to be perceived and treated in the world.

For many of us it worked for years, if not decades. But now as we age with PPS and the usual other age-related conditions, we experience age-inappropriate loss of function, loss of income, social contact, and even appropriate healthcare. This just at a time when society is in flux and we need better access and holistic health care, not box ticking and generalised care. This is as true, if not more true, for the psychological side of living with PPS which can trigger us going down all possible rabbit holes hoping to find 'The Answer' to our physical impairment or pain.

Appropriate Psychological Support

My concern is that the type and availability of appropriately experienced psychologists and therapists trained in the real-life challenges of disabled people is sadly lacking. What is offered is often totally inappropriate for post-polio patients and polio survivors. The social context and real lived experience of those of us with a lifelong knowledge of polio and living in the world as disabled people doesn't fit well into the simplistic reductionist psychological therapies and approaches on offer. Anyone who has encountered a telephone triage to 'sign post you to an appropriate therapy service' will know just how frustrating and often alienating and disheartening the experience can be.

Therapy for disabled and people with chronic conditions requires a broad experience of the medical and psychological world of disabled people. And it also requires a deep under the social context and a commitment to social justice for our clients and patients. When I see in the pathway - psychology - it is hard for me not to worry that the fundamental emotional, medical, and social issues that should be at the core of a psychological service for polio survivors is not appreciated. If we are subjecting PPS patients to the same reductionist and manualised approaches that are widespread, we will fail to meet the needs of PPS patients and others living and ageing with long term and chronic conditions.