

Understanding the needs of polio survivors

By CAROL LEVIN, The British Polio Fellowship

Orthotics are essential in improving mobility, relieving pain, and supporting independence, especially for individuals with neuromuscular conditions. But when it comes to caring for polio survivors, a one-size-fits-all approach simply doesn't work. Their unique history, patterns of muscle weakness, and decades of adaptation mean that orthotic care must be highly personalised and responsive.

For those living with the late effects of polio or post-polio syndrome, their needs often differ significantly from individuals with other neurological conditions like stroke or multiple sclerosis (MS). Many have lived with polio since childhood, often using orthoses to achieve the highest level of mobility possible, only to face the distressing reality of losing that ability again later in life due to PPS.

Lyndsay McNicol, Senior Orthotist at Guy's and St Thomas' NHS Foundation Trust, highlights this uniqueness: "What sets polio survivors apart is the wide variability in how polio affects each person. But one thing they often share is an incredible resilience and determination to adapt and keep going, no matter how difficult the circumstances."

UNDERSTANDING THE INDIVIDUAL JOURNEY

Taking the time to understand a polio survivor's personal and medical history is crucial. It helps guide the design, selection, and fitting of orthoses that genuinely support their lifestyle and goals. This collaborative, patient-led approach is the key to successful outcomes.

Take Tony Howlett, a polio survivor from West Yorkshire. He contracted polio as a baby during the 1947 Hull epidemic and has worn specially designed orthotic boots ever since to support his shortened right leg. After multiple leg-lengthening operations, Tony now wears a custom boot with a 5-inch raise at the toe and 9.5-inch raise at the heel, an adaptation of the original 4-inch and 7-inch corrections he once needed. He remains physically active and mobile, working closely with his orthotist every 15 months to ensure his devices evolve with his needs.

CHALLENGES OF POST-POLIO SYNDROME

Post-polio syndrome (PPS) is a complex neurological condition that can appear decades after the original infection, bringing on new or worsening symptoms such as muscle weakness, fatigue, and joint pain. These effects, combined with years of compensation and adaptation, make orthotic management more complex.



Tony Howlett pictured with his wife

WORSENING MUSCLE WEAKNESS AND GAIT ADAPTATIONS

PPS often causes a gradual decline in muscle strength, sometimes even in areas that weren't previously affected by polio. This widespread weakening can result in instability, joint deformities, and increased difficulty walking or standing.

- **Supporting without overloading:** Orthotics must strike a delicate balance, providing support to weakened muscles while avoiding additional strain on muscles that have been compensating for decades. Tailored adjustments help avoid fatigue and further weakening.

Tony, for instance, uses a KAFO with a leather covered aluminium ring top to support his weakened leg. "When my hip is bad," he says, "I go to the full-length calliper and rest my body weight on the metal ring."

- **Respecting compensatory gait:** Many polio survivors have developed highly individualised walking styles. These patterns, while not biomechanically ideal, often serve them well. Orthoses should aim to improve alignment and reduce strain, without attempting to 'fix' deeply embedded habits all at once, which can cause discomfort or instability.

- **Intact sensation:** Unlike conditions like diabetic neuropathy or spinal cord injuries, polio survivors typically retain full skin sensation. This makes them more aware of pressure points, rubbing, or poor fit. Lightweight, breathable materials and precise fitting are essential to prevent sores and ensure consistent wear.

"With polio patients," Lyndsay explains, "it's essential to align treatment with what they find most disruptive. If someone reports back pain due to a leg length discrepancy, despite visible muscle weakness, our focus should be on correcting the discrepancy. Addressing issues that aren't their top priority can result in poor compliance."

MANAGING FATIGUE AND CONSERVING ENERGY

Neuromuscular fatigue in PPS can be more limiting than muscle weakness itself. This type of fatigue is intense, long-lasting, and not always related to the level of activity.

- **Boosting efficiency:** Orthoses such as AFOs and KAFOs can reduce energy expenditure during walking, stabilise joints, and reduce the mental and physical strain of worrying about falls.
- **Modern materials matter:** Many survivors still use old-fashioned leather and metal callipers, which are heavier and less efficient. Today's materials are lighter, more comfortable, and energy-saving, but transitioning to them may take time and reassurance.

EMOTIONAL AND PSYCHOLOGICAL CONSIDERATIONS

Many polio survivors have lived with orthoses for decades and have developed deep-rooted identities around independence and perseverance. Some may view new or additional support as a sign of decline.

Tony has used orthoses for 78 years. "I've had a short leg all these years and I've adapted. It's just normal to me."

But when he began needing support on his non-polio leg in his 60s, it was a difficult shift: "That leg was always the strong one."

- **Normalising support:** It's important to help patients understand that using orthoses doesn't mean failure, it's about staying independent and active for longer.
- **Building trust:** Open, respectful conversations about goals, preferences, and modern orthotic options can ease the

emotional burden and promote a sense of partnership.

- **Tailoring the approach:** PPS affects everyone differently. Some may struggle more with leg weakness, others with fatigue or upper body involvement. Orthotic care must adapt to the individual's movement patterns, routines, and goals. "Polio survivors often have evolving needs," Lyndsay notes. "An orthosis that worked years ago may no longer be appropriate. Whether we're adjusting existing devices or introducing orthoses for the first time, it's vital to set realistic goals and expectations, always rooted in the patient's lived experience."

ORTHOTIC SUPPORT THAT RESPECTS THE WHOLE PERSON

Polio survivors face a unique combination of progressive muscle weakness, fatigue, and long-standing movement adaptations. They often retain full sensation, which makes comfort and fit even more important. Without orthotic support, many would face significant mobility challenges.

As Tony puts it: "I'd really struggle without my callipers. With them, I can get around using sticks or two crutches. If they didn't work for me, I'd probably have to lean heavily on a rollator or need a wheelchair."

With thoughtful, personalised orthotic care, it's possible to improve stability, reduce pain, conserve energy, and make daily life more manageable. Above all, respecting each survivor's journey, listening to their goals, and working together can make a meaningful impact, one that goes well beyond mobility.

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