

Optimal clinical pathway for polio survivors

(including the late effects of polio and post-polio syndrome)



Endorsements and approvals

Endorsements

This pathway is endorsed by The British Society of Physical and Rehabilitation Medicine (BSPRM), The Association of Chartered Physiotherapists Interested in Neurology (ACPIN), The Royal College of Nursing (RCN), The British Association of Prosthetists and Orthotists (BAPO), The Royal College of Occupational Therapists (RCOT), The British Sleep Society (BSS), The British Psychological Society (BPS), The Chartered Society of Physiotherapy (CSP), The Neurological Alliance (NA), Wales Neurological Alliance (WNA), The Neurological Alliance of Scotland (NAoS) and The Northern Ireland Neurological Charities Alliance (niNCA).

Approvals

The Association of British Neurologists (ABN) is pleased to give its approval to this optimum clinical care pathway. We recognise the after effects of polio can be devastating for individuals and this pathway recognises their complex needs.

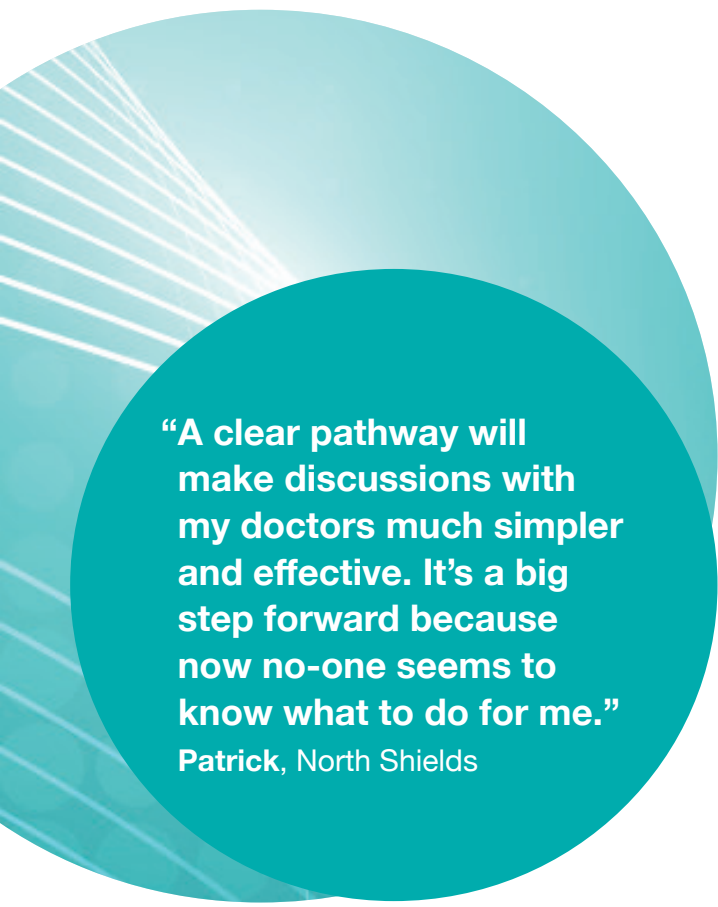
The Royal College of General Practitioners (RCGP) give their approval to the pathway for polio survivors.



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1. Summary of the optimal clinical pathway for polio survivors



“A clear pathway will make discussions with my doctors much simpler and effective. It’s a big step forward because now no-one seems to know what to do for me.”

Patrick, North Shields

The optimal clinical care pathway sets out what good treatment, care and support looks like for polio survivors in the UK. This pathway is for all patients who have had polio and are experiencing new and/or deteriorating symptoms that need informed, co-ordinated management. It is not limited to those who meet the full criteria for post-polio syndrome (PPS).

The pathway is designed to support local systems, health boards, providers and health professionals to commission and deliver quality and efficient services to meet the needs of this patient population. It is expected to be flexible enough to be adapted to local population needs and resource. **Local pathways should ensure that polio survivors with concerning or complex symptoms, and diagnostic uncertainty have timely access to a specialist multi-disciplinary team (MDT) with experience in late effects of polio (LEOP)/PPS for a comprehensive assessment, whilst also providing for consistent coordinated disability management in the community.**

The optimal clinical care pathway recognises the benefits of keeping care local when possible. Given the prevalence of LEOP/PPS in the population, variation in local neurorehabilitation service provision, and workforce expertise in polio/LEOP/PPS, it is essential that clear referral pathways and funding arrangements are in place to ensure that patients receive specialist assessment, diagnosis and treatment in a timely manner to prevent avoidable functional deterioration and disability.

Principles of the pathway

1. Polio survivors with first or new symptoms should be assessed and diagnosed by a specialist PPS service with **an experienced MDT team**. Atypical presentation and/or rapid deterioration may require assessment to exclude differential diagnosis.
2. Polio survivors with a diagnosis of LEOP/PPS should have a **care plan**.
3. The **specialist PPS service** should be responsible for development of the personalised care plan, overall co-ordination, and ongoing management with local and/or regional referral in line with the care plan.
4. Polio survivors should have a **named worker/care coordinator** that is responsible for care coordination, assessment, triage, signposting, and liaison with relevant services in line with the care plan.
5. Ongoing care and support should be **kept local** to the patient when possible.
6. Care is **person-centred** and promotes shared decision-making.
7. **Care is coordinated** around the patient’s needs, underpinned by communication between specialist PPS service and local and regional teams.
8. Polio survivors have access to **integrated services** with access to neuropsychological and mental health services across the pathway.

2. Context

2.1 Overview of polio, LEOP and PPS

Poliomyelitis is an acute infection causing permanent neurological damage, most prominently to the motor neurons but also the brain. More than 90% of infections are inapparent and 4-8% recorded as minor¹. Up to 1% develop the acute major illness leading to lifelong apparently stable muscle weakness or paralysis in the legs, arms and torso, affecting mobility, breathing, and skeletal development. Weakness of the bulbar muscles can lead to swallowing, voice and sleep issues².

Lifelong needs: Over the lifetime, many experience **late effects of polio (LEOP)**. These include joint deterioration, overuse injury to stronger areas, pain, fatigue, sleep apnoea, increased gait disturbance, respiratory infections, osteoporosis, osteoarthritis, falls, and fractures. A history of polio increases the risk of comorbidities such as cardiovascular, respiratory and endocrine conditions³. Around 60% develop new muscle weakness leading to further muscle atrophy and worsening pain, fatigue and breathing issues -the neurological condition **post-polio syndrome (PPS)**⁴.

Careful management/treatment may slow symptom progression and improve function and quality of life. LEOP/PPS is rarely life-threatening, although some develop breathing and swallowing difficulties with serious complications.

LEOP: Late effects of polio
PPS: Post-polio syndrome

2.2 The UK polio survivor cohort

UK epidemics: Most people living in the UK today with the long term effects of polio contracted the infection during epidemics between the 1930's and 1962, peaking between 1947 and 1957 when the vaccine was introduced. Over 76,000 notifications were recorded between 1932 and 1962 across the UK but did not fall to zero until 1999.

This is a minimum figure due to the difficulty of diagnosing polio in infants and the number of unreported/undiagnosed milder cases.

Roughly 65% of these notified cases were aged under 15yrs with ~35% under 4yrs⁵. About 10-20% died, 10-20% were considered to have recovered without clinical consequence, 10-40% severely affected, 15-60% moderate and 20-30% mild.

UK numbers today: Projecting forward to 2023, using published survival rates, the **estimated minimum number with a history of acute poliomyelitis from the UK epidemics still living today is 47,000**. They are typically aged over 50, mostly in their 60s and 70s⁶.

Currently, a growing cohort of polio survivors presenting in clinical practice contracted polio abroad prior to moving to the UK. They are younger, and of working age – 16% attending the PPS service at the Lane Fox Unit, Guy's and St. Thomas' Hospital, London are <50.

Last wild polio cases: UK 1980s, Europe 1990s, world-wide many countries in the 2010s, a couple still endemic.

2.3 Original treatment, outcomes and trauma

Typical treatment included some weeks in isolation in a fever hospital, some months to years in an orthopaedic hospital with outpatient clinics until adulthood or completed rehabilitation. Remembering that most polio patients were infants and children, this would have been very traumatic.

Following this, there was no polio specific care; more severe cases needed orthopaedic interventions for musculoskeletal issues and some needed respiratory support.

Polio survivors typically have now self-managed their condition for decades without informed care and with coping styles acquired in the 1950s and 60s.

Assessment of the disability due to the residual impact of polio was limited by the tools of the time; for example, if appliances were needed for stability, or if a special school was essential.

Subclinical damage: Significant motor neuron damage from the original infection was subclinical and undiagnosed, though this can also lead to late effects and PPS decades later⁷.

The psychological impact of the original polio and its treatment were not addressed and the traumatic isolation, extended physical restriction in casts and splints, separation from family, challenging and often painful rehabilitation have left many finding it difficult to talk about their condition, their feelings and worries.

2.4 Patient experience today

Care is compromised by the overall lack of awareness and understanding amongst health professionals, including primary care, about polio and LEOP/PPS. In The BPF Big Survey in 2022, polio survivors reported that 60% of general practitioners (GPs) didn't recognise LEOP or PPS, reconfirming the results of a 2010 GPnet survey where 69% of GPs rated their knowledge of PPS as low. A 2016 YouGov poll of the general public found that only 11% had heard of LEOP and 7% of PPS, compared to 83% had heard of MND.

Polio survivors report poor care outside of specialist clinics including failure to diagnose LEOP/PPS, misdiagnosis, assumptions that weak/atrophied muscles can be built up through exercise, failure to investigate early PPS symptoms such as difficulty breathing or swallowing properly, inadequate orthotics and shoe provision and maintenance, poor pain relief and inappropriate referral for surgery.

2.5 Health inequalities:

- Age, deprivation, ethnicity, disability and refugee status amongst other factors, indicate significant health inequalities facing this patient population.
- Ageing population require additional support, complex comorbidity management and support to access services.
- Immigration trends indicate an expected increase in patients presenting from abroad with a lack of coordinated care in place (India, Pakistan, Nigeria and Afghanistan, have all experienced polio outbreaks in the last 10 years).
- Polio survivors of working age require ongoing services and support to remain economically active where possible.
- LEOP and PPS are very significantly under-researched compared to other conditions with similar prevalence – resulting in a lack of knowledge, awareness, and provision of care. The average number of research papers is about 20 per year compared to 1,000 to 7,000 per year for other neurological conditions.
- Polio is unique in that the gap between the acute stage and later deterioration in symptoms can be many decades – poor care arises as polio is considered “extinct”, records from the acute stage are frequently lost and problems are not linked with the prior polio. Most experienced doctors have retired, reducing the skill base.

BPF: British Polio Fellowship
LEOP: Late effects of polio
MND: Motor Neurone Disease
PPS: Post-polio syndrome

2.6 Current provision of care (gaps/barriers)

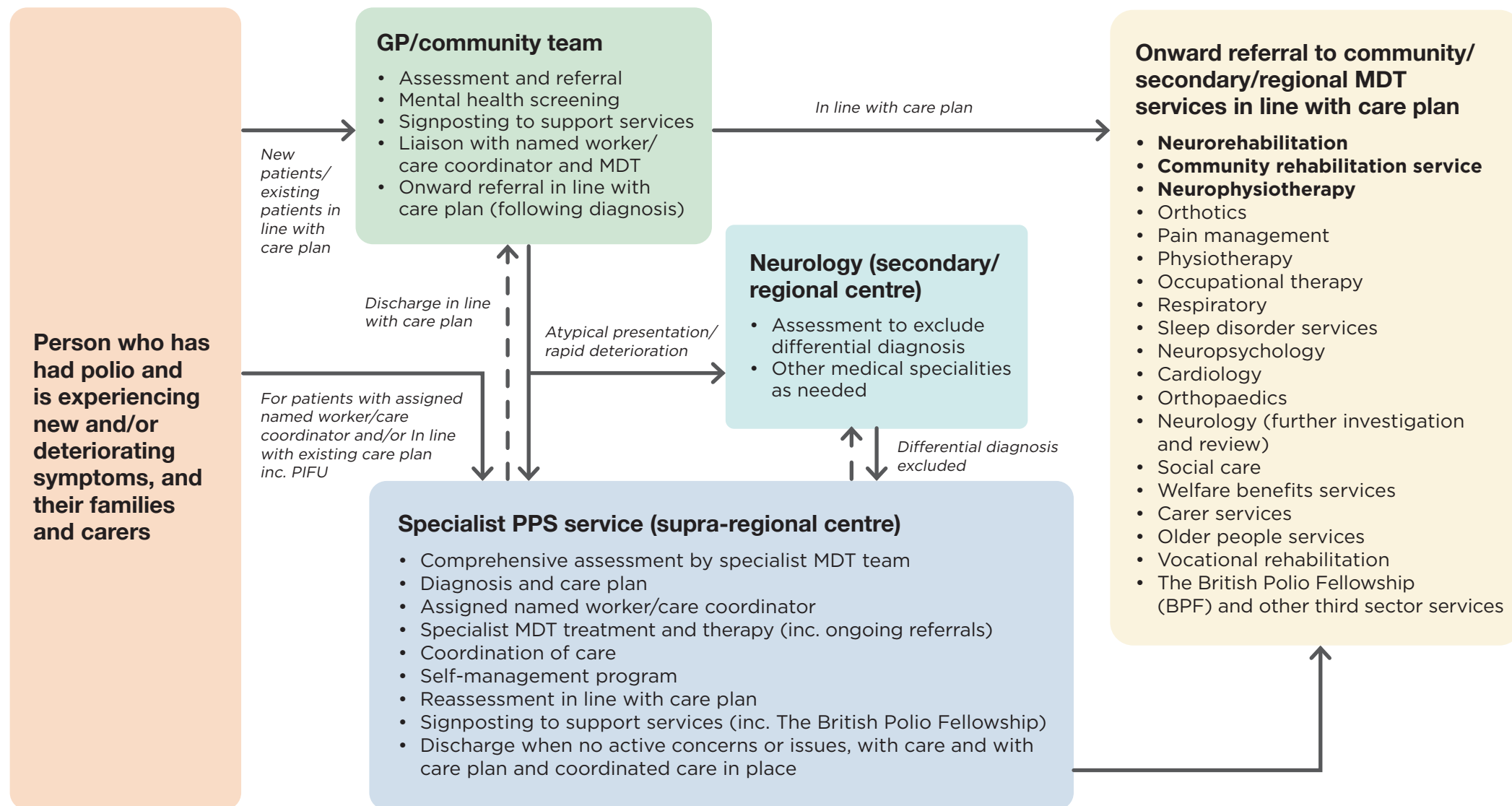
The provision and expertise around LEOP/PPS varies considerably in the UK. Local and regional neurorehabilitation teams vary considerably in capacity, resource and PPS expertise to provide long-term care and disability management for polio survivors.

Specialist PPS services have a central role in ensuring that care is coordinated, consistent and timely, and in communicating with the patient's local, regional and primary care team to ensure ongoing disability and comorbidity management. This leads to greater consistency and quality of care for patients but also cost efficiency savings in reduction of multiple separate professional referrals.

At present the PPS service at the Lane Fox Unit, Guys and St Thomas' Hospital, London is the only specialist PPS service in the UK.

3. Optimal clinical pathway

3.1 Pathway map



Information, education, advice, supported self-management, shared decision-making, family and carer support, access to research opportunities at all levels

BPF: British Polio Fellowship; MDT: Multi-disciplinary team; PIFU: Patient initiated follow-up

3.2 First or new presentation to diagnosis or reassessment

Polio survivors may experience a change or fluctuation of symptom(s) severity and new symptoms may develop over time. Common symptoms which drive people to present to a healthcare professional include functional deterioration, fatigue, new weakness, pain and shortness of breath and/or difficulty breathing at night.

Presentation in primary/community care:

Polio survivors experiencing new or deteriorating symptoms are likely to present in primary and community care services in the first instance. **Patients may not necessarily have knowledge of having previously had polio as a child and/or be aware of LEOP/PPS at the point of first presentation.** They may seek help for only one or two symptoms (pain, fatigue, balance..) and not link these to, or mention, a polio history. For some, new or worsening symptoms from a disease they thought they had 'defeated' may be challenging to address. For those who as very young children had a traumatic experience with the original polio, this may also awaken frightening memories and anxieties. Many find it difficult to express their needs.

Referral for specialist assessment/

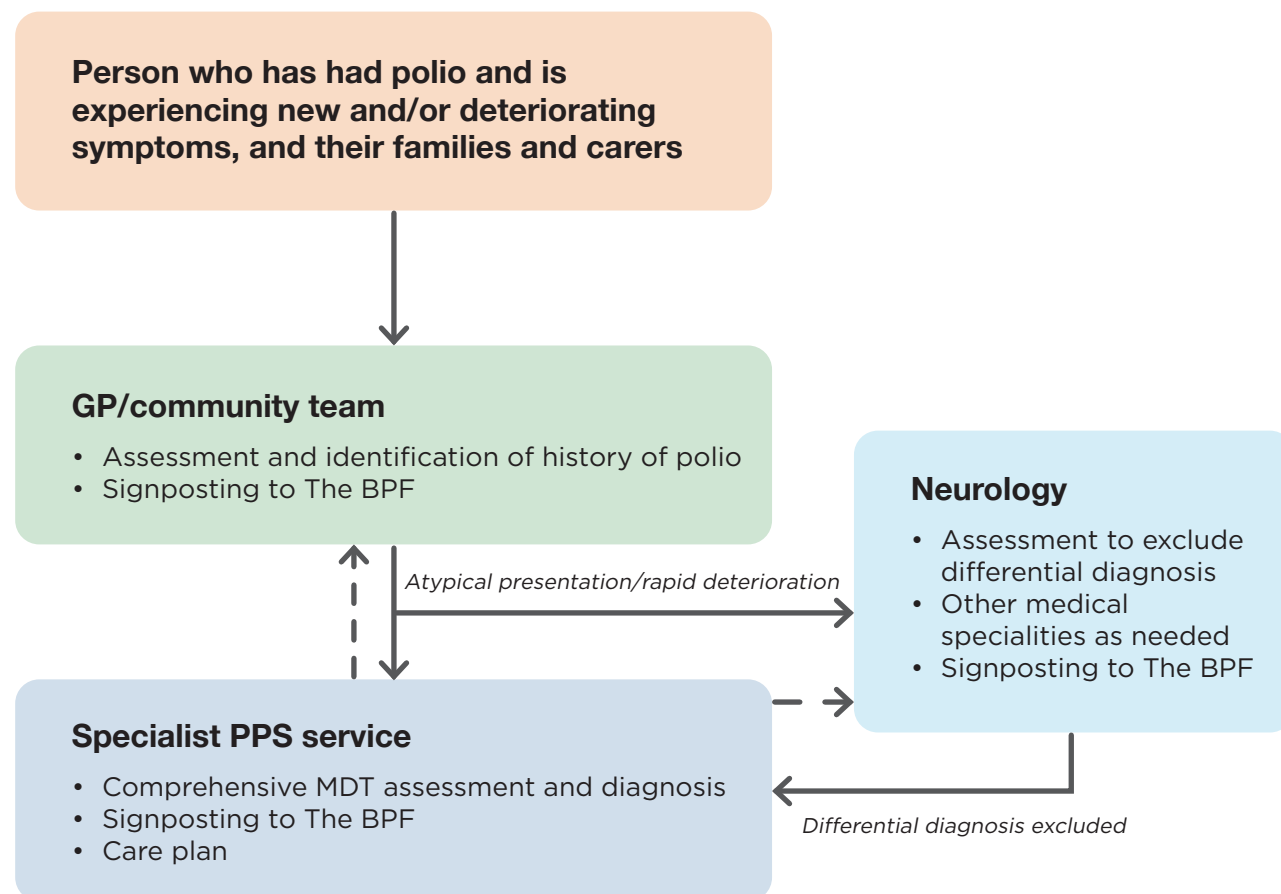
diagnosis: Patients presenting with functional deterioration and a history of having contracted polio should be seen by the specialist PPS service for comprehensive MDT assessment, diagnosis and management.

Patients with atypical presentations and rapid deterioration should be referred to a neurologist to exclude differential diagnosis.

It is important that the following are available in primary/community care:

- Workforce information and education about LEOP/PPS.
- Information, resources and signposting to support services for polio survivors and families.
- Clearly defined PPS, neuroscience, neurorehabilitation and mental health pathways with clear referral proformas.

First presentation to diagnosis:



BPF: British Polio Fellowship; LEOP: Late effects of polio; PPS: Post-polio syndrome; MDT: Multi-disciplinary team

3.3 Ongoing symptom management and treatment

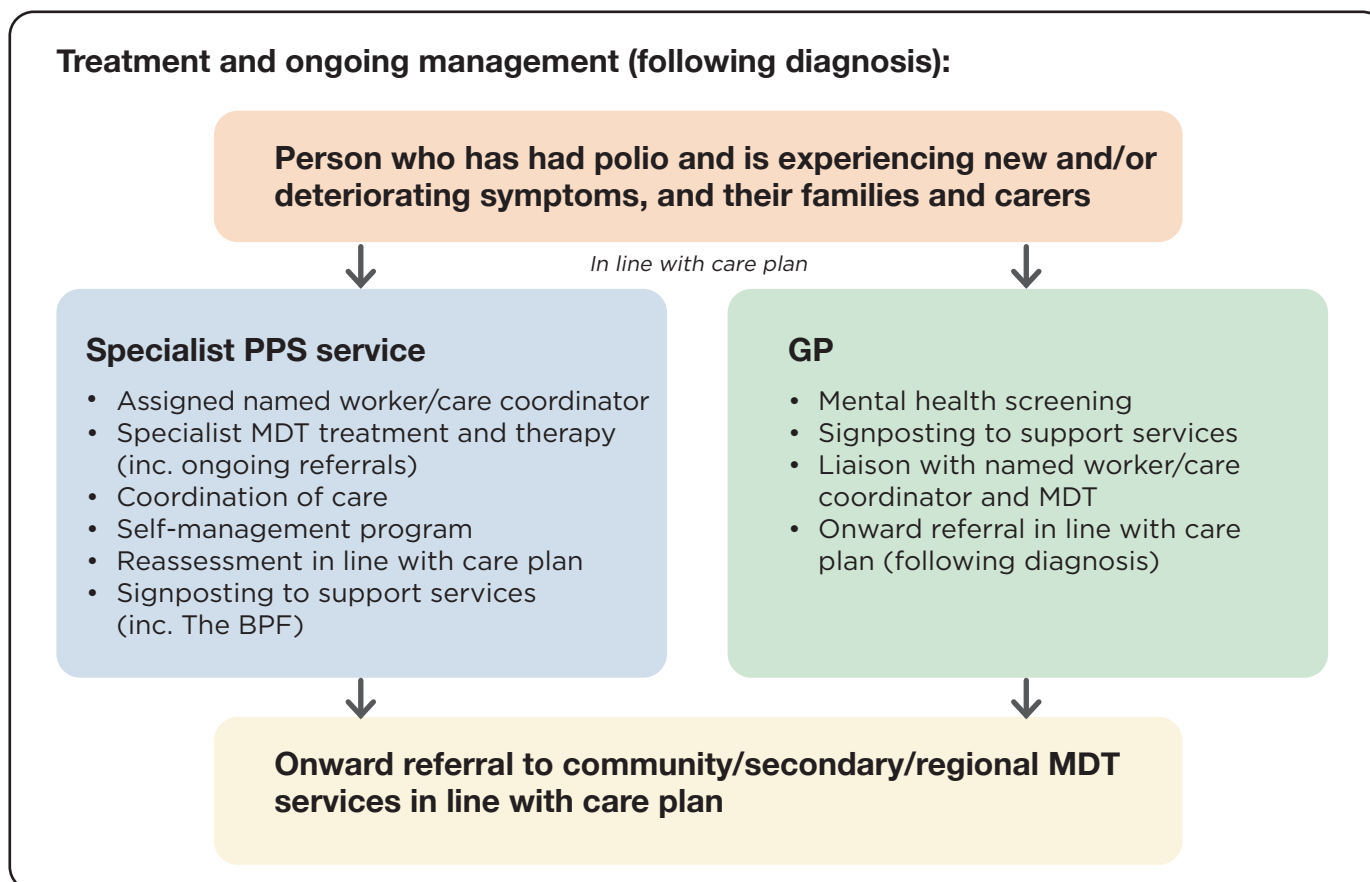
Following assessment and diagnosis, treatment and ongoing management⁸ will require⁹:

- coordination of care by the specialist PPS service.
- a named worker who is responsible for overall coordination of care.
- personalised care plan developed in partnership with the patient, and their family and carer(s), to support treatment, self-management and holistic needs.
- established links and ongoing communication between specialist PPS service, the patient's GP and MDT network.
- access to personalised neurorehabilitation:
 - early introduction of non-invasive ventilatory aids prevent or delay further respiratory decline.
 - personalised, supervised exercise programmes and advice on fatigue management designed to avoid neuromuscular overuse.
 - support groups, regular group activities.
 - monitoring respiratory function and the use of ventilatory aids.
 - patient education.
 - weight loss, adjustment, and introduction/review of properly fitted orthoses and assistive devices should be considered.
 - consideration of devices to support mobility.

- access to self-management advice including residential programme.
- reviews at regular intervals in line with patient need and/or as in response to new or persisting/deteriorating symptoms.
- access to neuropsychological support.
- access to vocational rehabilitation.
- established MDT network to meet patients' needs (inc. community, local and regional services where appropriate).

- signposting to The BPF and local support services for patient, family and carers.
- local funding arrangements in place.

Patient groups that may have specific pathway needs: older people, palliative care, permanent wheelchair users, refugees, orthopaedic needs that have not been addressed during skeletal development, patients that contracted polio outside of the UK, and complex comorbidities e.g. dementia.



3.4 Specialist PPS service: assessment, diagnosis and care co-ordination

A specialist PPS service provides access to assessment, treatment and management by an experienced full MDT (see Appendix 1 for service model). The PPS service at the Lane Fox Unit, Guys and St Thomas' Hospital, London is currently the only specialist PPS service in the UK. The Lane Fox Unit specialist PPS MDT includes a rehabilitation medicine consultant, physiotherapist, occupational therapist, orthotist, respiratory consultant, and neurologist with expertise in PPS. The service is best placed to coordinate overall care and utilise the referral to local care services as well as secondary or tertiary services.

Referrals:

- new patients or those patients presenting with new symptoms.
- patients with an existing LEOP/PPS diagnosis who develop new weakness, new symptomology or experience significant deterioration requiring reassessment.
- cases of diagnostic uncertainty and/or complex symptom or co-morbidity management.

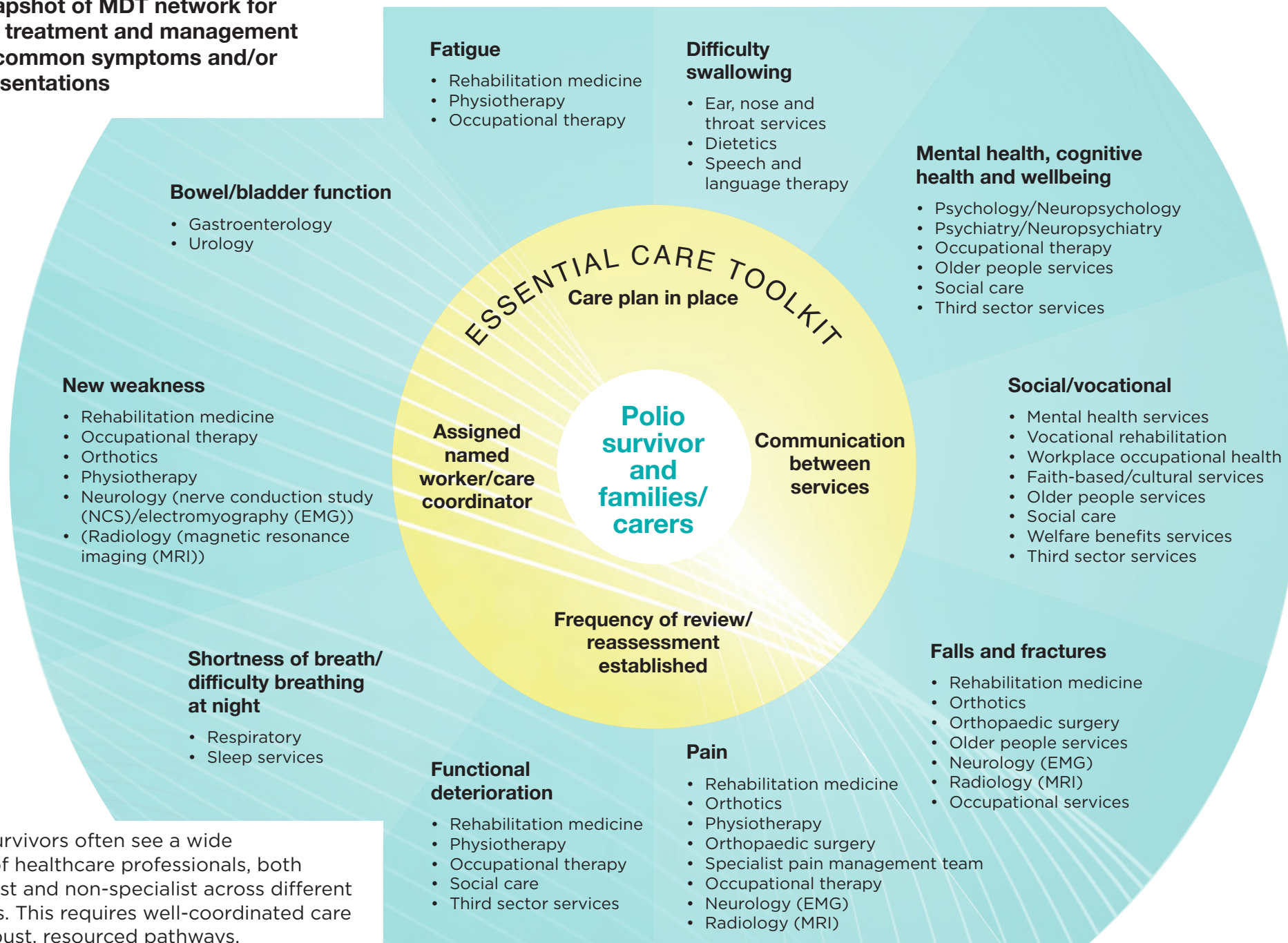
Services include:

- comprehensive MDT assessment and diagnosis.

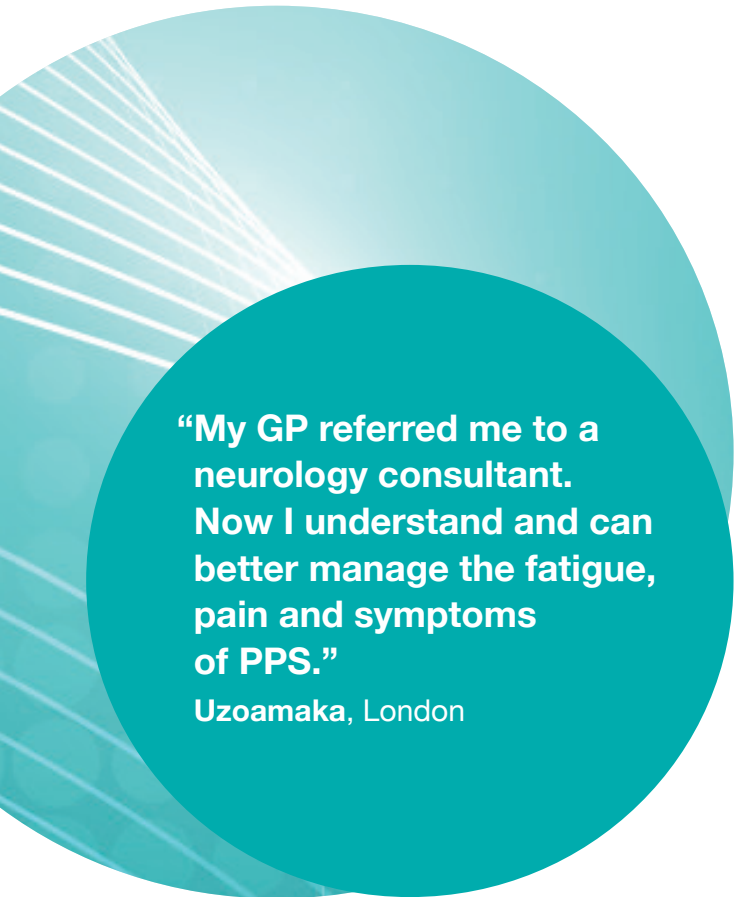
- specialist multi-disciplinary management of LEOP/PPS including:
 - specialist polio/PPS complex orthotic service.
 - individually tailored fatigue and activity/exercise management designed to avoid neuromuscular overuse.
 - assessment and management of respiratory function and sleep disordered breathing.
 - close liaison with surgical specialties particular foot and ankle, knee, hip, spine and upper limb specialist surgery including decisions around joint replacement, arthrodesis, and osteotomies to improve pain and stability.
- symptom management advice including residential self-management programme.
- advice around assessment, investigations for patients undergoing anaesthesia.
- coordination of care including liaison with community/local/regional services for ongoing care.
- recommendations for aids, adaptations and other equipment as well as services to support function.
- referral to mental health services.
- referral to vocational rehabilitation services.

- appointments may be face-to-face, by telephone or by video to meet the needs of the patient.
- arrangements for patient transport and overnight accommodation, supported by the service may be required.
- individual funding requests (England/Northern Ireland)/individual patient funding requests (Wales)/peer approved clinical system (Scotland) may be required.

3.5 Snapshot of MDT network for the treatment and management of common symptoms and/or presentations



Polio survivors often see a wide range of healthcare professionals, both specialist and non-specialist across different settings. This requires well-coordinated care and robust, resourced pathways.



“My GP referred me to a neurology consultant. Now I understand and can better manage the fatigue, pain and symptoms of PPS.”

Uzoamaka, London

3.6 Good practice principles

1. Polio survivors with first or new symptoms should be assessed and diagnosed by a specialist PPS service with an experienced MDT team:

Atypical presentation and/or rapid deterioration may require assessment to exclude differential diagnosis. Post-polio syndrome is foremost a clinical diagnosis. For example, an EMG or nerve conduction study is not routinely used to diagnose PPS. Often the best an EMG study can show is signs of previous polio infection or identify another cause of weakness. It is not a diagnostic test for PPS. This is not often understood by the medical community and has perpetuated the idea the condition does not exist. This is often very disempowering for patients and fails to fully acknowledge the functional deterioration that polio survivors experience. Local and regional rehabilitation services vary considerably in capacity, resource and expertise around PPS. At diagnosis, the diagnosing physician should agree a personalised care plan with the patient and provide the patient with:

- a comprehensive, detailed, tailored diagnosis and assessment that combines communication, discussion and education about polio, LEOP and PPS.
- an assessment within the WHO International Classification of Functioning, Disability and Health (ICF)¹⁰.
- information around prognosis in terms of level of function deterioration (a common concern).

- an opportunity for polio survivors and their families to discuss uncertainties and anxieties about the diagnosis.
- an opportunity for polio survivors and their families to develop informed expectation around future goals.
- mental health screening.
- information regarding comorbidities.
- written information and signposting to The BPF and other local support services.
- electrophysiology tests (EMG and nerve conduction and spinal MRI) only if required to exclude other causes.

2. Polio survivors with a diagnosis of LEOP/PPS should have a care plan: A care plan is a written document regarding the outcome of a care planning process for an individual with one or more long-term conditions. The care plan should be developed in partnership with the individual, their families and carers, health and social care professionals. The written plan may be referred to as “care and support plan”, “personalised care plan” or “anticipatory care plan” or another name.

3. The specialist PPS service should be responsible for the development of the personalised care plan, overall co-ordination, and ongoing management with local/regional referral in line with the care plan: Local pathways should ensure that polio survivors have access to a specialist PPS service for assessment, treatment and management by an experienced full MDT. See page 10 for more details.

4. Polio survivors should have a named worker/care coordinator that is responsible for care coordination, assessment, triage, signposting, and liaison with relevant services in line with the care plan:

A named worker/care coordinator will facilitate communication, and the assessment and management of new symptoms. The named worker/care coordinator is responsible for maintaining contact, triage, signposting, and liaison with relevant services and the GP as required and in line with the care plan. Depending on the patient's needs and the agreed care plan the named worker/care coordinator could be a member of the specialist PPS MDT team such as a rehabilitation medicine consultant, neurophysiotherapist, occupational therapist, neurology specialist nurse. Depending on the patient's needs, and in line with the care plan the named worker/care coordinator could also be another health professional with experience of lifelong disability management such as the GP.

5. Ongoing care and support should be kept local to the patient when possible: Services that can be offered locally to reduce patient need to travel include:

- telephone/virtual consultations can be offered by the specialist centre for stable patients that don't need examination by a specialist.
- online self-management programme.

6. Care is person-centred and promotes shared decision-making: Polio survivors and their families and carers should be provided with the necessary information and support to make decisions about their care and treatment. This includes information to enable them to manage expectations and make plans for the future.

7. Care is coordinated around the patient's needs, underpinned by communication between specialist PPS service and local/regional teams: Care should be coordinated and consistent with good communication between services. The specialist PPS service should take responsibility for coordinating care (in line with the care plan) while the patient is under the service. Discharge from the specialist PPS service should be accompanied by the allocation of a named point of contact/named worker/care coordinator in the primary/community team to continue the coordination of care for stable patients e.g. GP, neurology nurse.

8. Polio survivors have access to integrated services with a connection to neuropsychological and mental health services across the pathway: Mental health and neuropsychological support is essential throughout the person's journey, promoting adjustment and self-efficacy, and preventing isolation, sense of hopelessness and mental and physical deterioration. Psychological support needs to be at the appropriate level of expertise and intensity for the individual. Professional expertise and competencies should include awareness of cognitive impact of neurological conditions and fatigue, as well as the psychological impact of living

with a long-term neurological condition. Polio survivors may require psychological support regarding the adverse experiences of their early polio care, and to address maladaptive coping strategies.



“I have to describe my symptoms and history over and over again for each new healthcare appointment – a care plan would make communication more effective and less stressful.”

Jerry, Tamworth

4. Implementation of the pathway

4.1 Pathway efficiency savings

The pathway will lead to greater consistency and quality of care for patients and is expected to provide cost efficiency savings:

- early diagnosis.
- reduction of multiple separate professional referrals.
- reduction of costly and inappropriate investigations.
- reduced pressure on primary care.
- access to appropriate treatment (improve outcomes, experience and reduces long-term cost).
- reduced reassessment.
- improved global functioning leading to improved economic contribution, decrease rate complications eg fractures from fall, deformity through orthotic management, improved quality of life and mental health through peer support, education and fatigue management.

4.2 Recommendations to local Integrated Care Boards and Health and Care Boards

- **Establish local pathways** and funding structures to ensure timely access to the specialist PPS supra-regional service at the Lane Fox Unit, and allow for ongoing local disability management and care coordination led by specialist PPS service.
- **Routine data collection** of nationally agreed coded data to enable the publication of comparative datasets to support pathway/service delivery.
- **Coproduce local pathways** with polio survivors, their families and carers. Partner with The BPF and local support services to engage polio survivors in communities at risk of health inequalities in the development of local pathways.
- **Review of workforce** to meet the needs of the LEOP/PPS patient population.
- **Establish a clinical rehabilitation network** with input from all local providers of rehabilitation services including primary, secondary, tertiary health care, mental health, social care, vocational, independent and third sector providers, ensuring inclusion of specialist PPS service and The BPF.
- **Expand community rehabilitation provision** to meet need of LEOP/PPS patients.
- **Develop rehabilitation models** to address functioning needs.

4.3 National recommendations

- The British Polio Fellowship (BPF), The British Society of Physical and Rehabilitation Medicine (BSPRM), Association of British Neurologists (ABN), Association of Chartered Physiotherapists in Neurology (ACPIN), and the Lane Fox Unit PPS service to establish a **national education programme** for health professionals.
- Third sector organisations, research funders, academics, clinicians and The BPF to work together to define and implement a UK-wide register of LEOP/PPS to improve **real world data collection** about polio survivors living in the UK.
- The BPF, the Lane Fox Unit PPS service and professional organisations that represent multi-disciplinary workforce for polio survivors including the BSPRM, ABN, ACPIN, and the Lane Fox Unit PPS service to develop and implement a **UK-wide clinical network** for polio, LEOP and PPS to improve the treatment, care and support of polio survivors and their families and carers.

4.4 Case studies that demonstrate the advantages of specialist, coordinated and consistent care for polio survivors

A 66-year-old female patient presented to her GP for more than five years with symptoms including extreme fatigue, leg, and back pain. Blood and thyroid tests did not yield noteworthy results and her symptoms were attributed to overexertion and/or lacking nutrients. No link was made to the patient's history of polio. Following symptom deterioration and persistent muscle weakness the patient asked to be referred to the Lane Fox Unit. A diagnosis of PPS was confirmed following MDT assessment. The patient remains under the care of Lane Fox for treatment and disability management. Local referrals have also been coordinated for physiotherapy and orthotics.

An active 72-year-old patient with scoliosis, fatigue, left leg weakness and worsening lung capacity was referred to the Lane Fox Unit for physiotherapy. The physiotherapist observed her breathing fast during a consultation and suggested she ask her respiratory and sleep consultant about trying a night ventilator. The patient's consultant, who also observed the breathlessness, agreed she should use a Biphase Positive Airway Pressure (BiPAP) machine at night. The patient went on to complete the Lane Fox PPS self-management course and has over time improved. The course helped her remain active and taught her how to listen to her body and take necessary actions to manage symptoms.

A polio survivor with a cancer diagnosis attended hospital for treatment due to last seven to ten days. A delay in recognising polio as a neurological condition, the lack of knowledge about its late effects and the patient being kept totally bedridden for ten days, exacerbated prior polio weakness and prolonged recovery. As a result, the 75-year-old was left as an in-patient and unable to walk for more than twenty-three weeks. The patient eventually succeeded in getting referred to a neurological rehabilitation facility in Leeds and has slowly regained mobility and received appropriate ongoing care.

For many years, a Midlands-based patient received adequate polio care from his GP. When he began to present with worsening muscle pain and fatigue, the patient was referred to a neurological consultant at a nearby NHS regional centre with a MDT for neurorehabilitation. The 68-year-old patient has been waiting for more than 12 months for a first appointment and potential diagnosis. The patient feels increasingly unsupported, and his wellbeing has deteriorated. He is exploring alternative therapies to alleviate chronic pain.

5. Supporting resources

5.1 Clinical guidance to support the pathway

The BPF Expert Panel has produced guidelines for the management of post-polio syndrome (PPS) for health care professionals along with a range of factsheets for polio survivors. The panel includes a wide range of clinicians. Key documents include:

- **‘Post Polio Syndrome: A guide to management for health care professionals’**, this is an in-depth review of polio and PPS along with management of the primary symptoms experienced by polio survivors www.britishpolio.org.uk/guides-hc-professionals
- **‘Post Polio Syndrome: A guide to management for health care professionals - Quick Reference Guide’**, this is a two page summary of the key guidance www.britishpolio.org.uk/guides-hc-professionals

The Royal College of GPs’ e-learning course on PPS www.elearning.rcgp.org.uk/course/info.php?id=249

The European Federation of Neurological Societies Guideline:

Farbu, E., Gilhus, N. E., Barnes, M. P., Borg, K., de Visser, M., Driessen, A., . . . Stalberg, E. (2006). **EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force.** [Evaluation Studies]. *European Journal of Neurology*, 13(8), 795-801. updated (2011): Farbu, E., Gilhus, N. E., Barnes, M. P., Borg, K., Visser, M. d., Howard, R., . . . Stalberg, E. (2011). Post-polio syndrome. In N. E. Gilhus, M. P. Barnes & M. Brainin (Eds.), *European Handbook of Neurological Management* (Vol. 1): Blackwell Publishing Ltd.

Recent review papers:

- Lo, J. K., & Robinson, L. R. (2018). **Post-polio syndrome and the late effects of poliomyelitis. Part 1. pathogenesis, biomechanical considerations, diagnosis, and investigations.** [Review]. *Muscle Nerve*, 58(6), 751-759. doi: 10.1002/mus.26168
- Lo, J. K., & Robinson, L. R. (2018). **Post-polio syndrome and the late effects of poliomyelitis: Part 2. treatment, management, and prognosis.** [Review]. *Muscle Nerve*, 58(6), 760-769. doi: 10.1002/mus.26167
- Koopman, F. S., Uegaki, K., Gilhus, N. E., Beelen, A., de Visser, M., & Nollet, F. (2011). **Treatment for postpolio syndrome.** *Cochrane Database of Systematic Reviews*, 2011(2), i-89. doi: 10.1002/14651858.CD007818.pub2.
- Rosenberg, D. C., Rovito, C., & Martinez, S. (2021). Post-Polio Syndrome: Background, Management and Treatment *Physical Medicine and Rehabilitation Clinics of North America; Clinics Review Articles* (Vol. 32, pp. 467-600): Elsevier.

Evaluation of the Lane Fox Unit post-polio syndrome self management programme

Curtis A, Lee JS, Kaltsakas G, Auyeung V, Shaw S, Hart N, Steier J. **The value of a post-polio syndrome self-management programme.** *J Thorac Dis* 2020;12(Suppl2):S153-S162. doi: 10.21037/jtd-cus-2020-009

National health service links:

England: www.nhs.uk/conditions/post-polio-syndrome/

Scotland: www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/post-polio-syndrome/

Patient.info professional: www.patient.info/doctor/post-polio-syndrome

5.2 The British Polio Fellowship services for polio survivors, their families and carers

The British Polio Fellowship is the only UK national charity dedicated to supporting and empowering polio survivors, their families and carers.

Services include:

- free telephone support services.
 - Advisory/Expert Panel: To assist with the production of factsheets, and guide on general polio medical related matters.
 - information and advice guides: on polio and late effects, factsheets on pain management, swallowing, exercise, anaesthesia, medication, bone health and more.
 - activities and local events: local networks for coffee/lunch, trips out, rehabilitation exercise classes.
 - national events: Indoor Games, information days, roadshows etc.
 - online discussions: on respiratory problems, heart matters, orthotics, sleep issues, disability rights, legal matters.
 - grants: towards heating, mobility aids, holidays, and others.
 - news: quarterly magazine, monthly email, website, social media posts.
- working with partners : such as the Neurological Alliance, worldwide polio organisations including the European Polio Union (EPU), Disability Rights UK and many others.
 - being a voice for polio survivors.

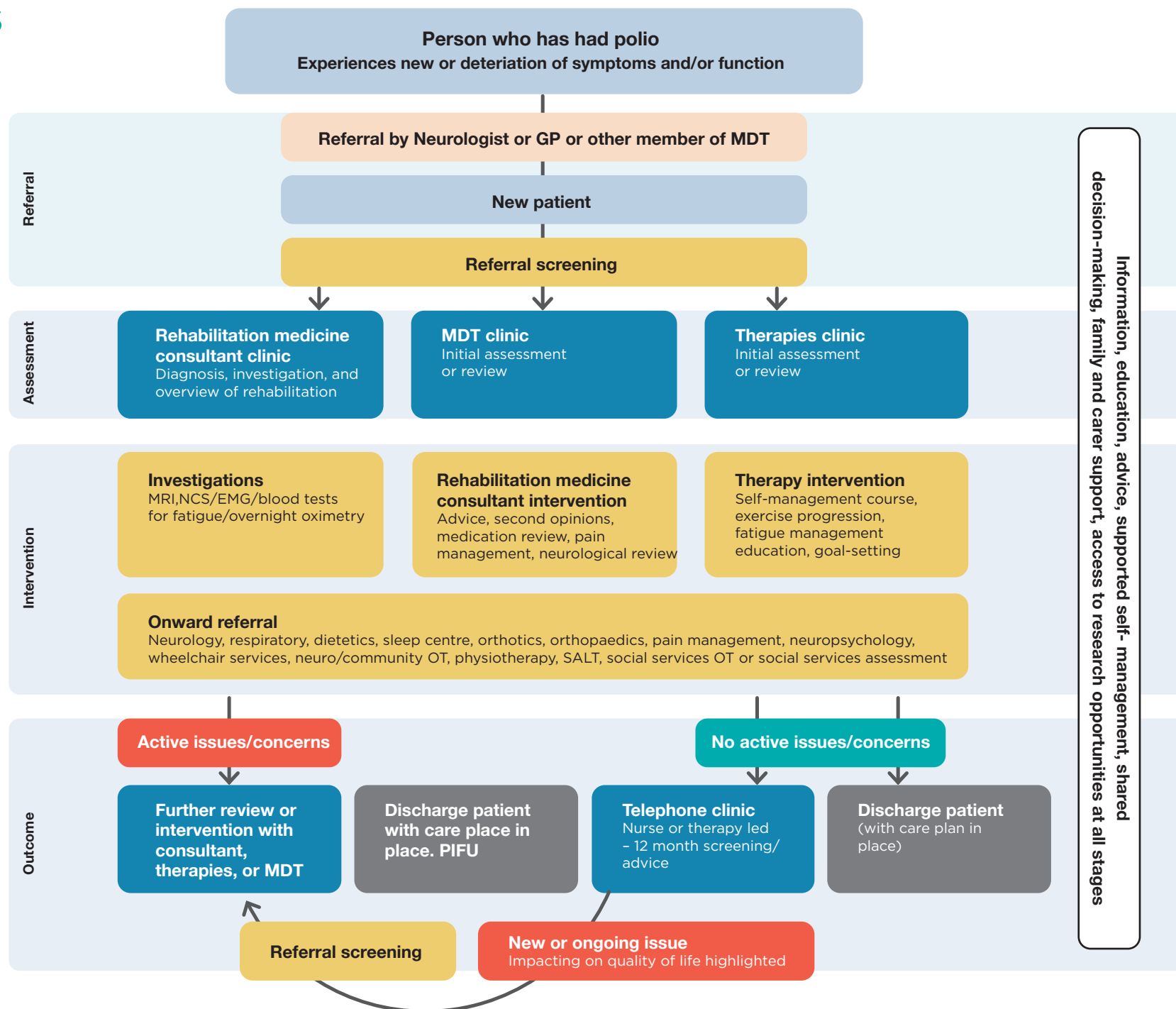


www.britishpolio.org.uk

6. Appendices

6.1 An example pathway model describing integrated MDT services required to allow management of patients who have had polio.

Source: Lane Fox Unit, Guy's and St Thomas' Hospital, London



MDT: Multi-disciplinary team
MRI: Magnetic resonance imaging
NCS: Nerve conduction study
EMG: Electromyography
PIFU: Patient initiated follow-up

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6.3 Glossary of terms

Care plan: A care plan is a written document regarding the outcome of a care planning process for an individual with one or more long-term conditions. The care plan should be developed in partnership with the individual, their families and carers, health and social care professionals. The written plan may be referred to as “care and support plan”, “personalised care plan” or “anticipatory care plan” or another name.

More information can be found here:

- Personalised care and support plans (England) www.england.nhs.uk/personalisedcare/pcsp
- Individual care plans (Wales) www.gov.wales/sites/default/files/publications/2019-04/public-patient-guide-to-individual-care-plans-for-people-with-long-term-conditions.pdf
- Anticipatory care plans (Scotland) www.nhsinform.scot/care-support-and-rights/decisions-about-care/future-care-planning/

Patient initiated follow-up (PIFU): A follow-up system that gives patients and their carers the flexibility to arrange their follow-up appointments as and when they need them. They are used for individuals on an inactive pathway i.e. because they are experiencing a period of stability but not deemed appropriate for discharge from a service lest they experience a deterioration in symptoms/ functioning. Local ICS/health boards/trusts will have their own arrangements for PIFU pathways and these may vary. Please refer to local arrangements. General information about PIFU can be found here: www.neural.org.uk/wp-content/uploads/2021/06/Guidance-20210623-PIFU-principles-June-2021.pdf

6.4 Pathway steering group

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Notes:

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