



Palliative Care

Information for people with
polio or Post Polio Syndrome (PPS)

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The British Polio Fellowship is a registered charity in England and Wales (1108335) and in Scotland (SC038863).
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The term 'palliative care' is negative and frightening for many, because of its associations with end-of-life treatments. However, while it is a regime of care only offered to people with chronic, complex, life-threatening illnesses, it is a positive, life-enhancing approach to treatment focused on helping people manage their symptoms.

What is palliative care?

The National Institute for Clinical Excellence (NICE) states that palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of care
- Offer a support system to help people live as actively as possible until death
- Offer a support system to help the family cope during the illness and in bereavement

Palliative care, polio and PPS

Unlike traditional medical approaches that are fixed on 'cure', palliative care is about offering relief from acute, chronic symptoms and their associated conditions, and providing a better quality of life with as much independence as possible. For a small number of people with acute PPS symptoms, this could mean helping manage life-threatening complications with breathing, for example, and, in turn, associated conditions like sleep disorders.

The development of new, debilitating symptoms after you worked so hard to overcome the original polio illness can be very difficult to come to terms with. It can also trigger distressing memories of the treatment you may have experienced when you first contracted polio. For many people with polio or PPS, this can lead to depression.

Because palliative care is a holistic approach, taking the whole person into account, it addresses these kinds of challenges, too. It is a care concept that is as concerned for your social, emotional and spiritual wellbeing as it is your physical condition. It also recognises the need to support families and carers.

Who provides palliative care?

The hospice movement has been the driving force behind advances in palliative care over the years. Today, palliative care is available through both the NHS and directly through charitable, palliative care organisations. The chances are your treatment will be provided by a combination of the two, as the NHS palliative service works closely with the voluntary sector to provide patients with seamless care.

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NHS

The NHS provides general palliative care in the community via district nurses and GPs. Where there are complications, patients are referred to a specialist palliative care service within the NHS.

Overseen by a consultant in palliative medicine, such services offer complex symptom management through clinical nurse specialists (in carer care these are known as Macmillan Nurses) working in the community. Additional specialists are also available, such as psychologists who support patients after receiving a terminal diagnosis.

Each local organisation has its own criteria defining who is eligible for palliative care. If you want to access a palliative service, in the first instance, ask your GP for a referral.

Voluntary Sector

Hospices are not just places where patients with a terminal illness go to die; they are also centres of palliative care excellence. They offer 24/7 care until a suitable, specific, symptom-management programme has been developed. They also provide respite care for patients, enabling their carers to take a break.

If you don't want to leave your own home, some hospices also provide a hospice-at-home service, delivered by nurses who work closely with a palliative care consultant and your GP. Alternatively, there are hospices that provide day-care services. These centres are often invaluable sources of support for carers too.

In addition, and consistent with a holistic approach to care, most hospices offer alternative therapy services, such as massage and reflexology, free of charge for patients and, sometimes for carers, too.

If you would like more information about palliative care, please contact

The National Council for Palliative Care:
The Fitzpatrick Building
188-194 York Way
London N7 9AS

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Email: enquiries@ncpc.org.uk
Website: www.ncpc.org.uk

If you would like more information about the late effects of polio or Post Polio Syndrome, please contact

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