

Palliative Care

Introduction

This factsheet is for anyone who had polio or has Post Polio Syndrome (PPS) who would like to learn more about palliative care.

The term 'palliative care' is often negative and frightening for many, because of its associations with end-of-life treatments. However, while it is a regime of care offered to people with chronic, complex, life-threatening illnesses; it is a positive, life-enhancing approach to treatment focused on helping many people manage their symptoms.

The National Institute for Health and Care Excellence (NICE) defines palliative care as:

"The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."

"The aim of general palliative care is to provide:

- *Information for the person and their carers, with 'signposting' to relevant services.*
- *Accurate and holistic assessment of a person's needs.*
- *Co-ordination of care teams in and out of hours and across boundaries of care.*
- *Basic levels of symptom control.*
- *Psychological, social, spiritual, and practical support.*
- *Open and sensitive communication with the person, their carers, and professional staff."*

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.

Most areas of the UK have Proactive Care teams which includes GPs, consultants, nurses, physiotherapists, occupational therapists, social workers and speech therapists. Having a Proactive Care assessment involves: looking at your whole needs, those of people close to you, making contingency plans, carers, wishes while in hospital, and rather than aiming to plan for the end of life, it aims to plan for the life that you want under the conditions you want. An example is that sometimes individuals have to go into hospital several times a year for their conditions. At times, this causes great stress and upset and also could possibly be dealt with at home if the right resources are available. Moreover, often when 999 is called, the ambulance service does not know about individuals with complex needs. Having a plan in place stating what your medical

and social needs may be and your preferences can relieve much stress should you need to go to hospital this way.

NHS

Depending on your area, the NHS provides general palliative care in the community via district nurses, GPs, physiotherapists and occupational therapists. Where there are wider complexities or complications, patients can be referred to a specialist NHS Palliative Care Service.

Overseen by a consultant in palliative medicine, such services offer complex symptom management through clinical nurse specialists working in the community. Charities such as Sue Ryder, Marie Curie, Macmillan Cancer Support and others also fund specialist nurses who work alongside the NHS. 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 centers 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 centers 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

Telephone: 020 7697 1520

Email: enquiries@ncpc.org.uk

Website: www.ncpc.org.uk

Medical Disclaimer

The information given in this factsheet is not personal medical advice and by providing it The British Polio Fellowship and our medical advisors do not undertake any responsibility for your medical care. Before acting on any of the information contained in this factsheet, you should discuss the matter with your GP or any other medical professional who is treating you.

Author

This factsheet was produced by the British Polio Fellowship Expert Panel.

Version 2: Lead author Dr. Mark Fabrowski, GP.

With thanks for their help and advice to Ana Draper, (Macmillan Psychotherapist), Dr. David Wright, Dr. George Kassianos and Dr. Christopher Bennett.

Date: September 2020 **Date:** 29/06/2020

The British Polio Fellowship Contact Details

The British Polio Fellowship

CP House, Otterspool Way,

Watford Bypass, Watford, WD25 8HR

Freephone: 0800 043 1935/ 01923 889 501

Website: www.britishpolio.org.uk

Email: info@britishpolio.org.uk

© The British Polio Fellowship.

The British Polio Fellowship is a company limited by guarantee and registered in England and Wales No 5294321 and Scotland No SCO38863, Registered Charity No 1108335