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"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." — Dame Cicely Saunders, founder of the modern hospice movement

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

1. What is Palliative Care

The term Palliative Care may seem solemn or frightening because of its associations with end-of-life care. It is true that care for people at the very end of life is an important part of Palliative Care, but Palliative Care is much broader than this.

Palliative Care is a holistic approach to care which promotes quality of life for people with serious, progressive illness, and their loved ones. It is a positive, life-enhancing approach which helps people live their life to the full. The World Health Organization defines Palliative Care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other problems physical, psychological, social, and spiritual.

Palliative Care is important for people with all serious, life-threatening illnesses, and may be delivered at every stage of the illness. It may be different from other forms of healthcare, which tend to focus on treating the underlying illness, because Palliative Care focuses instead on enhancing quality of life. However, for many people, Palliative Care can be delivered alongside other treatments that are life-prolonging or treat the underlying disease. Palliative Care can also be delivered at later stages, when no more life-prolonging treatment may be possible or if

someone decides they want to focus solely on comfort and stop life-prolonging treatment.



Diagram showing that Palliative Care includes end-of-life care, but it is much broader than end-of-life care

Palliative Care is provided by a variety of different healthcare professionals who work to help a person with a life-threatening illness. No two people are the same, nor do they have the same needs. The way a person experiences Palliative Care will vary depending on their individual circumstances. Examples of Palliative Care can include:

- Accurate and holistic assessment of a person's needs;
- Open, sensitive communication with the person with life-threatening disease and their loved ones;
- Providing practical advice for the person and their carers, including 'signposting' to relevant services;
- Co-ordination of various care teams and professionals involved in the care of the patient;
- Helping to control physical symptoms such as pain and shortness of breath, including through the use of medication, but also using approaches which do not involve taking medicines;
- Addressing any emotional or spiritual challenges which a person faces as they come to terms with their life-threatening illness;

- Discussion of prognosis, and possible future events which a person with a life-threatening illness and their family may face;
- Discussion of what matters most to the person with a life-threatening illness, including helping them to make decisions about how and where they want to be cared for;
- Forming a plan to ensure the person with life-threatening illness can live their life to the fullest, in a way which aligns with their wishes as much as possible.

2. Palliative Care, Polio and PPS

For a small number of people with acute PPS symptoms, there could be 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 be difficult to cope with emotionally (it can lead to depression, low mood or anxiety or even problems with mental health generally).

Because Palliative Care is a holistic approach, taking the whole person into account, it addresses these kinds of challenges too. It is an approach that is as concerned for your social, emotional, and spiritual wellbeing as well as the physical condition. Palliative care can also help meet the needs of families and carers of people affected by polio and PPS.

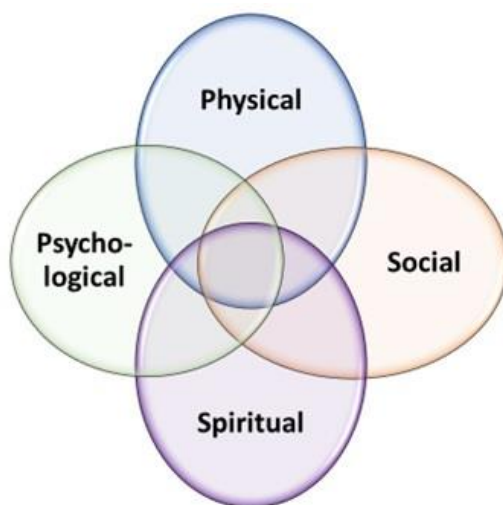


Diagram showing the four major domains of Palliative Care: the physical, psychological, social, and spiritual domains

3. Who provides Palliative Care?

Generalist Palliative Care is a term for palliative care which can be provided by all healthcare professionals, in every healthcare setting. All healthcare professionals have a responsibility to deliver Palliative Care when a person needs it. High quality Palliative Care is constantly being delivered across the health service, in different ways, depending on the needs of individuals.

Examples of healthcare professionals who are involved in delivering components of Generalist Palliative Care include: General Practitioners, District Nurses, home care staff, hospital doctors and nurses, physiotherapists, occupational therapists, and social workers. People may receive generalist palliative care while living at home, while resident in a care home, while an in-patient in hospital, or a mix of these. In most cases, generalist Palliative Care is provided by the National Health Service in the UK.

Specialist Palliative Care also exists. This helps people who need more specialist care. This may include when a person's symptoms are more difficult to keep under control, or they have particularly complex medical and personal circumstances. Specialist Palliative Care includes medical doctors for whom Palliative Medicine is an area of specialist expertise. Specialist Palliative Care is often based from specialist units, which may be called *hospices*, but the specialist team can help to deliver care for people who are at home, in-patients in hospital, in-patients at a hospice unit, visitors at Palliative Care Day units, residents of care homes, or people who move between these settings at different times of their life. Healthcare professionals from the Specialist Palliative Care also help to advise other healthcare professionals about how to manage the needs of people with life-threatening illness.

Examples of healthcare professionals who are involved in delivering Specialist Palliative Care include: doctors who specialise in Palliative Medicine, Clinical Nurse Specialists, specialist physiotherapists and occupational therapists, counsellors, chaplains, and nurses who work in a hospice.

Specialist Palliative Care is also available free of charge in the United Kingdom. Depending on where you live, it may be provided by the NHS. However, in many cases Specialist Palliative Care is provided by charitable organisations which are

largely funded through charitable donations. Examples include national charities like Marie Curie and Sue Ryder Care, but may also include smaller, independent hospice charities. If you wish to see a healthcare professional from a Specialist Palliative Care team, then you should speak to your GP in the first instance who may be able to refer you.

4. Thinking About the Future

None of us know with certainty what the future holds. It is important for everyone to think about what their wishes may be for the future if they were to become unwell and need care. This is even more important after a person is diagnosed with a life-threatening or progressive illness. Letting your loved ones, and your healthcare team, know how you wish to be cared for in the future can help you receive care which matches your wishes, and stop things from happening which you do not want to happen.

If you have a life-threatening or progressive illness, your doctor or nurse may ask you what your wishes may be in the future if or when you become more unwell. Healthcare professionals refer to these kinds of conversations as **Anticipatory Care Planning**. When having such conversations, it may be helpful to think “I hope for the best, but I need to prepare for the worst.”

These conversations are useful to develop a plan about when you become more unwell: whether it is best to prioritise treatments which may be life-prolonging, or treatments which may prioritise comfort, or reach a balance between these. When having such a conversation, the questions you may be asked to help form the Anticipatory Care Plan include:

- Who is important to you? Who do you want to be with if/when you become more unwell?
- When/if you become more unwell, you may not be able to communicate your own wishes about your care. Who would be your spokesperson to represent your wishes in such a situation? Have you appointed someone as a Lasting Power of Attorney who would have legal authority to make decisions about your welfare if you were unable to communicate?
- Where do you want to be cared for if/when you become more unwell? For example, at home, in hospital, or in a care home?

- What resources can we put in place to support you to remain at home for as long as possible?
- Is there anything you definitely would not wish to go through during your illness?
- Where do you want to be cared for at the very end of your life? For example, at home, in hospice, in a care home, or in a hospice?

Discussions like this about the future often involve decisions about Cardiopulmonary Resuscitation (CPR). CPR is an invasive treatment that can be appropriate for some people whose heart and lungs stop working suddenly, especially as an unexpected emergency. However, in other cases, a person’s heart and lungs stop working as an expected, natural part of reaching the end of their life. CPR is likely to be the wrong treatment to offer people with progressive, advanced conditions who are reaching the end of their life. This is why, when a person has a life-threatening or progressive condition, the doctor may come to the conclusion to introduce a **Do Not Attempt CPR decision (DNACPR)**, which they will discuss and explain to the affected person. Having a DNACPR decision in place means that, when the time does come when that person is reaching the end of their life, the healthcare team can focus purely on comfort.

Thinking about these issues and having these conversations can be challenging and may be upsetting. However, it is very important to try to have these plans in place in advance, so that everyone who cares for you can try to meet your wishes and needs – now and in the future.

For example, a person with a serious illness may not wish to be admitted to hospital and may wish to be cared for at home with a focus on comfort. However, if there is no documented anticipatory care plan in place, they may become more unwell and not be able to communicate their wishes. In this case, they would likely be admitted to hospital. In hospital there may be many investigations, and treatments given, and there may be great stress and upset as this person is not being cared for in their home environment. For patients with serious life-threatening and progressive illness, having plans about care made in advance means that they are more likely to receive care they want, access to the right resources, and live in a way which is right for them.

5. Key points

If you would like more information about Palliative Care, please contact:

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2. **Version 2: September 2020.** Lead author Dr Mark Fabrowski, Family Medicine Physician. With thanks for their help and advice to Ana Draper, (Macmillan Psychotherapist), Dr David Wright, Dr George Kassianos and Dr Christopher Bennett.
3. **Version 3: September 2022.** Lead author Dr Shaun Peter Qureshi, Palliative Medicine Physician, with help from Dr Mark Fabrowski, Family Medicine Physician.

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