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## Treatment Escalation Plans: What are They, and Why Do They Matter?

*Dying Matters Awareness Week attempts to raise the profile of the care that exists for dying individuals and their families. It also aims to highlight some of the gaps that exist in the support structures for people who are dying – and for those that they leave behind.*

*Treatment Escalation Plans (TEPs) aim to empower patients who are frail or with life-limiting illnesses, in conjunction with their family and the GP/doctor responsible for their care, to explore the treatment options available to them – and ensure that appropriate preparation has been made for a supported, symptom-free end of life period. Angela Cooke, Practical Development Lead*

*explains what TEPs are, and why they're so important.*

## **What is a Treatment Escalation Plan?**

According to Angela, a Treatment Escalation Plan “enables both the discussion about their treatment plan, and the documentation of a patient’s wishes.” It’s a collaborative document that’s made in consultation with a multidisciplinary team of GPs and nurses – often comprising several different service providers – as well as the patient and their support circle.

In the event that the patient becomes too unwell – or insufficiently lucid – to specify how they would like to be treated upon the worsening of their condition, a TEP informs clinicians of the patient’s wishes, while relieving the patient’s family of shouldering the entirety of that decision-making burden themselves.

TEPs don’t constitute a legally binding document. Rather, they’re designed to be malleable, flexible; open to regular updates and adjustments by patients and their loved ones.

**“TEPs aren’t a tick box exercise,” says Angela. “They’re a discussion between people – a sharing of information.”**

Developed in 2017 by Professor Robin Taylor of Lanarkshire, Scotland, the TEP was derived from a similar type of document known as a Hospital Advance Care Plan (ACP).

ACPs allow the patient to specify their preferences as to where and how they would prefer to die, and whether or not they want to be resuscitated. ACPs also have an emotional, psychosocial aspect, that empowers patients to outline their wishes regarding the use of any religious or spiritual practices at the time of their death.

While ACPs are still widely used – and indeed, are designed to function *alongside* TEPs, rather than as their replacement – ACPs still have their setbacks. As Angela explains,

“The advantage of having TEPs as opposed to ACPs is that they’re very specific about *treatment* – about each individual patient’s comorbidities and

medical history. ACPs can be too broad. TEPs concentrate on the treatment part of it, as well as taking into account the patient's other medical conditions.”

**With a TEP, a life-limited patient can specify their exact preferences when it comes to the treatment itself** (do they want to be given antibiotics in the case of a chest infection, for instance?) as well as choose how far they want that treatment to go. For instance, if oral medication is not possible, a patient is able to specify whether or not they wish to receive further treatment.

A patient can also specify their preferred place of treatment and death, as well as whether or not they want to be admitted to an acute hospital or spend their final days in the comfort of their own home, or a hospice. A patient is also able to make their wishes regarding resuscitation clear.

“TEPs concentrate on each patient's medical history, and on the likelihood of an emergency occurring with those conditions”, Angela adds. “When they do occur, what do the *patients* want? It's a very personal, very specific medical plan.

“A person does not have the right to demand treatment, but they have a right to be given information about their care, so as to enable them to express their wishes. The aim is to avoid further discomfort, and to provide an honest approach to a patient's care. Once this is achieved, preparations for a dignified death can commence.”

### **Why are Treatment Escalation Plans Important?**

The dying process can be quick or take some time. A dying person's cognitive mental state alters and affects their ability to make decisions; therefore, the need for planning and preparation is essential.

“Often, a person is caught off guard,” Angela explains, “and their condition deteriorates very quickly.”

This is something the coronavirus pandemic has thrust into a sobering spotlight. When patients who are frail or with incurable or life-limiting illnesses, such as cancer, contract an illness like COVID-19, not only can their condition go downhill quickly, but the probability of their full recovery may

be low.

‘Frailty’ is described as using one’s energy to live day to day. The frail often have other medical conditions, and individuals in this group tend to deteriorate rapidly from less serious illnesses. While the fit can recover quickly from such afflictions, the frail cannot; and, for this group, an illness like the common cold can lead to pneumonia. With every episode of illness, a frail individual’s performance level deteriorates, and eventually they become bed bound.

The Rockwood Frailty Score is an empirical tool used to measure how frail a person is, and how debilitating their current condition – or, in medical parlance, their ‘level of vulnerability to poor outcomes’.

“As patients get frailer”, Angela explains, “the medical conditions that they were previously living with quite comfortably will go haywire. We need to ensure that this high percentage of patients – the ones that are dying from the progression of age-related diseases – have the dignity and the care that is relevant for them, while keeping in mind the quality of their life.”

TEPs help patients and families work towards the best outcome for the life-limited individual – yet sometimes, sadly, the best course isn’t *always* life.

“It is possible to over-treat, at the detriment of the patient’s dignity. They’re already frail. You have to weigh it up – what is the patient actually going to gain from this? Is there a chance that additional treatment is going to cause more problems?”

Though TEPs can play a part in the prevention of this ‘over-treatment’ – and, if there are no better alternatives, help the patient die with dignity – Angela is quick to stress the need for care in terms of the message that a TEP sends out.

“TEPs are *definitely not* a choice made by professionals to stop a treatment. A TEP’s role is to present the patients with all the available options – to give them all the information they need to make an informed decision about their care, and to document their wishes.” A TEP stays with the patient, and their GP is given a copy of the document.

## The Future of Treatment Escalation Plans

Though the pandemic may have thrust the role of TEPs to the forefront of the clinical world, Angela believes it's "no knee jerk reaction – nor a phase, nor simply a reaction to the pandemic. TEPs are here to stay".

At ellenor, for instance, the document is already playing a major role in shaping the future.

Angela is currently leading training courses for staff with the aim of raising awareness around TEPs, while providing practical advice about how to have the difficult conversations involved.

[And, for Angela, the importance of TEPs goes beyond a purely professional or practical approach. As she explains, "over time, this document may be called something different, but the principle will remain the same. It's the principle that we have to protect."](#)

That principle? Putting the patient first. Giving them back the autonomy over their own future, empowering them to choose their own treatment, or –if all else fails –allowing them to die in dignity and peace, and with loved ones by their side.

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We are **ellenor**, a charity funded by the generosity of our local community, offering the best care and support to families facing terminal illness in Kent. We are the **only** charity in the county that provides hospice care for people of all ages – babies, children and adults - and their families. This includes pain and symptom relief, end of life care, respite, bereavement support and emotional and spiritual care.

Our Children's Hospice Care, formerly known as chYps, is provided in the comfort of the family home and spans across North and West Kent and the London Borough of Bexley. Adults living in Gravesham, Dartford and Swanley, receive care in their place of choice, including their own homes, at our Hospice in Gravesend and in local care homes.

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