
WHAT MATTERS MOST CHARTER

A personal & compassionate community approach to care and treatment planning

INTRODUCTION

Planning ahead is an important life task, and it remains important until the end of life. Planning involves a range of preferences about life choices, some of which involve preferences about care and medical treatments.

Towards the end of life, providing care that matches **what matters most** to people become increasingly important. Discussions about what matters most can begin within individuals' networks of family and friends, and be picked up by health and social care professionals to ensure that the care and treatments offered at the end of life continue to respect what matters most to that person. What matters most has implications for the person who is ill, their families and friends. This means decisions about future care and treatment need to be known by those involved in the person's care and support at home, as well as the professionals involved.

Discussion and recording of preferences about future medical treatments is known as Advance Care Planning (ACP). It has gained wide acceptance in health care as a way of discovering people's wishes about their care towards the end of life, but has become very focused on what NOT to do: what interventions to avoid, what treatments not to begin. While these wishes are important, knowing what treatment people don't want towards the end of life doesn't help us to wrap care around individuals in a way that matches what they DO want. It is time to change the conversation.

As an advisory group with representation from prominent healthcare organisations with experience of discussing ACP with patients, coupled with the evidence and reflection on the public's experience and perception of care planning, we have created this **Charter for Planning Ahead: What Matters To Me** that promotes a reframing of ACP conversations for both the public and health and social care professionals alike.

CHARTER PRINCIPLES

WHAT MATTERS CONVERSATIONS

1. What matters most conversations are a voluntary process that can be discussed at any point in life

These conversations can be had any time of life from childhood to the last years of life, during health or illness, at important anniversaries. People can (and do) change their minds about decisions they make depending on the circumstances in which they find themselves, so 'What matters' conversations need to be ongoing, involve different supporters and are not a single opportunity, or solely health-focused.

2. Promote a culture of openness about living as well as possible for the whole of life, including living with life-limiting illness

Encouraging a culture in our society that supports conversations about what matters most to us during living and dying as part of the natural cycle of life, allowing those that wish to discuss death or their ACP the acceptance, support and opportunity to do so.

3. What Matters conversations are centred on individuals and their significant relationships rather than being owned by healthcare

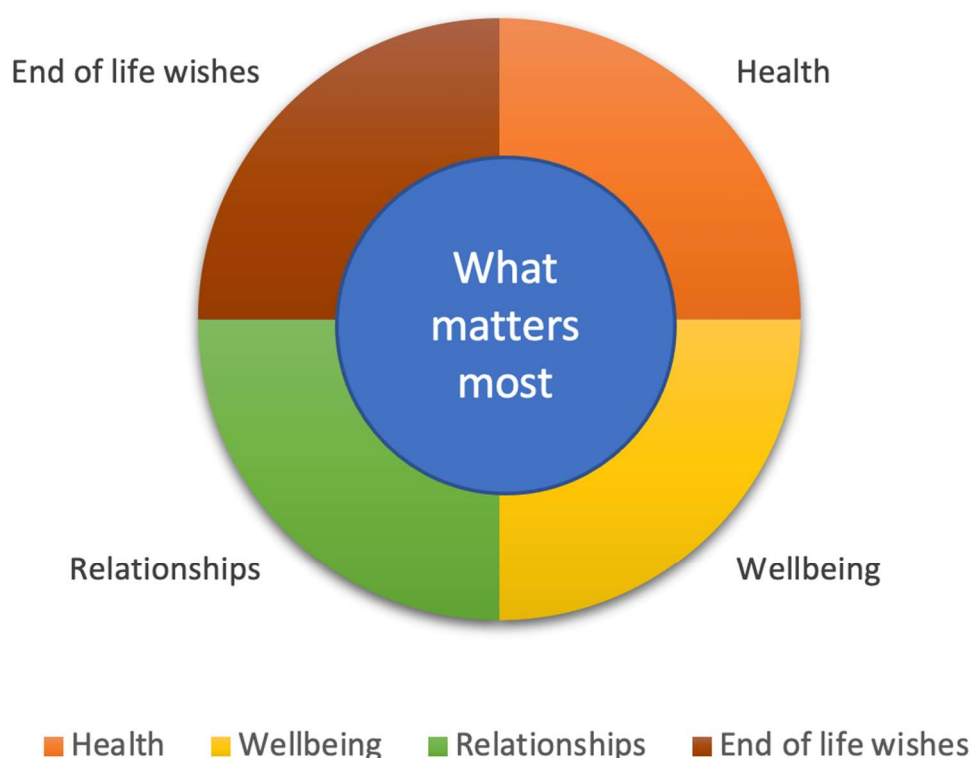
They encourage an individual to take ownership of what matters most to them, basing conversations on personal preferences and wishes. Supportive of individuals making **their** choices for **their own** living well, up to and including the end part of their life

4. To enable living well until death

Supporting everyone in our society to live as well as they can until they die, whether this is sudden or from a prolonged illness.

Figure: Planning ahead involves a range of preferences and values that influence life choices. Some of these are preferences about care and medical treatments but many are much broader. 'What matters most' conversations include all of these.

What Matters Most



IMPLEMENTING THE CHARTER

Key questions for individuals to support the gathering of key information for planning ahead: living with life limiting illness

Making the most of life

- **What matters most to me?**
- What may matter to me when I am less well or dying?
- What makes me feel most at peace?
- What are my networks of support and how can they be supported so that we all remain resilient and well cared for?

Care preferences

- When I am less well, where do I want to be cared for and by whom?
- Is there a point at which I would not want admission to a healthcare facility for further treatment which aims to preserve or extend life?
- Where might I prefer to be cared for when I am dying?
- Who do I want to make decisions for me if I am no longer able to make them for myself?
- Do I wish to make a will?
- Do I or my family have preferences for what happens after death?

Implications for health and social care providers

Part of the problem of healthcare ownership of ACP is the emphasis on avoiding unnecessary or unwanted treatments. This can make the conversation awkward, as it focusses on treatments that are to be avoided rather than concentrating on what can be done to make remaining life as good as possible. Beginning the conversation through **what matters most to people** allows for flow into acceptable levels of treatment to occur much more easily. Concentrating on what matters most opens the possibility of these discussions beginning in the community by the community.

Health and social care professionals' role includes opening up these conversations for patients when the right opportunity arises, and promoting a safe environment and space for them to be held. Care planning discussions should rarely be a single conversation. This is in part because it is an ongoing conversation not just with the person with the illness, but also with their families and those included in social networks of support. In addition, people change their mind about decisions they make depending on the circumstances in which they find themselves, so opportunities to review and refine plans are important.

Four main principles for health and social care professionals' consideration:

1. Seeking to discover **what matters most** in life to this individual. How they see themselves, what is important to them and what makes life worth living.
2. Seeking to discover what are the most important **social connections** for this person and how such connections could help in the event of life being restricted through illness.
3. Seeking to discover in the event of illness, how **health and social care decisions** can be used to support what matters most to this person. This includes some plans about urgent treatments to be embraced or avoided. Considerations might include what they would wish not to live without and what they think would make their life intolerably difficult.
4. In the light of the above, and with access to clear, realistic **information** about likely treatment options and outcomes, to help individuals map what treatments would most likely to match their own individual needs and hopes. The process of Planning Ahead enables professionals to focus their care on what matters most to people.

Receptivity of what matters conversations for existing medical and social systems

Use of these principles changes the discussion but not the recording of ACP: local variations of ACP and policy guidelines can continue to be implemented. Quality improvement methodology, to build continuous improvement, can be used to determine whether each of the Charter principles has been followed. This fits with the recommendations and principles of the Daffodil Standards for end of life care. The key to developing a system for Planning Ahead in this way is to focus firstly on ensuring what matters most to people to be able to live well right up until the end of their life is respected, and secondly to see which treatments they would like to avoid. Discussions of what **can be done** for people are much easier than those which limit treatment. Shifting the focus to start with what matters most to people fits with the general principles of personalised care.



