Advance care planning guidance in haematology-oncology

Includes best practice sharing by Dr Anthony Cunliffe, National Lead Medical Advisor, Macmillan Cancer Support

Definition of ACP[1]

A process of discussions between professionals, patients, and their families, which allows the patient to define and communicate their care and treatment preferences.

Key components of ACP[2]

When someone has a terminal illness, they may have to make a lot of decisions about what they want to happen including:

- **As the illness worsens, the person might become too unwell to make these decisions**, ie, they may lose mental capacity. ACP ensures that if they do become too unwell to make decisions, the people around them know what they want and can respect their wishes
- **ACP discussions can be introduced at any time in a patient's care pathway** with any professional involved in their care, as long as the professional has the confidence and relevant training of the essential principles of the ACP process
- **It generally isn't a one-off conversation**, but a series of opportunities for a patient to reflect, potentially with multiple health and social care professionals and their loved ones
- **It must be a voluntary conversation** and not all patients or carers will want to engage at any particular time
- **ACP isn't strictly a medical conversation** but should be approached in a holistic way, and should have shared decision making at its core

Importance of ACP in haemato-oncology[3]

- Haematological cancers are a heterogenous group of cancers with significant variation in outcomes between types. This makes ACP even more important and should be a natural part of conversations between the PLWC and the HCP
- ACP is not only relevant to those with limited survival, but is also important to anyone facing uncertainty regarding their prognosis or the impact of treatment on themselves and their loved ones
- 70% of PLWC who are admitted as an emergency will have a prognosis of less than 1 year to live, so they need to be given the opportunity to discuss what matters most for them if the time and situation is appropriate

Remember:
Outcomes from ACP can be variable and may not necessarily be medical, including individuals being able to identify and plan to achieve their wishes. However, considerations may involve the development of an advance statement of preferences for their care and treatment, or legal documents such as an ADRT or Lasting Power of Attorney.

What are some of the barriers to ACP?

- Lack of education and training for HCPs[4]
- Insufficient time[4]
- Lack of understanding between HCPs regarding who is responsible for starting the conversation[1]
- Limited patient participation in autonomous decision making[4]
- Cognitive and emotional barriers to discussion for patients[4]
- Lack of patient readiness and awareness of early discussion[4]

How can HCPs initiate ACP conversations?[2]

HCPs can consider asking one of these three core questions to initiate a conversation:

1. What do you want to happen in the future?
2. What do you not want to happen in the future?
3. Who do you want to speak for you if you can't speak for yourself?

- Once initiated, it's important to give the PLWC time to consider the questions and not be afraid of silence, verbalising this as needed. If the PLWC chooses to continue, the HCP can then ask them to consider more specific details
- The PLWC is also likely to have questions and concerns of their own to discuss. HCPs should try not to interrupt the PLWC's stream of consciousness, rather, follow the flow of the conversation and acknowledge their concerns
- Allow the PLWC to lead the conversation where possible, making sure the HCP asks the PLWC if they're comfortable talking about the topic before they start the discussion
- Making big decisions can be tiring. The PLWC should know that they can talk about ACP over several shorter conversations if they prefer. Over time, make a plan. The plan should always be made by the PLWC

ACP, advance care planning; ADRT, advance decision to refuse treatment; HCP, healthcare professional; PLWC, person living with cancer

1. Poveda-Moral, et al. Worldviews Evid Based Nurs 2021;18:254–63; 2. Marie Curie. Advance care planning. https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/advance-care-planning. Accessed 1 March 2023;
3. Blood Cancer UK. Advance care planning for healthcare professionals. https://bloodcancer.org.uk/healthcare-professionals/advance-care-planning-healthcare-professionals/. Accessed 1 March 2023; 4. Cheung JTK, et al. BMC Palliat Care 2020;19:30

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