

Why is ACP not already widely used?

There are several reasons:

- Many patients are not confident to consider how they would like to be cared for at the end-of-life.
- There are many different administrative forms and processes relating to ACP that can lead to confusion about how to put ACP in place successfully.
- If a patient receives care from several different professionals and organisations in different parts of the care system, who may not all be able to access all information about the patient.
- There is sometimes confusion over responsibility for introducing ACP conversations across professional and organisational boundaries.
- ACP for children with life-limiting illnesses is complex and ethically challenging. Currently most such children who die, do so in hospital and most commonly on a paediatric intensive care unit, despite growing evidence that family preferences are for end-of-life care at home.
- Perhaps an over riding reason is that many patients and their families are unaware of the process and the benefits it might offer them.

What can be done to improve the uptake of ACP?

To move to a situation where ACP becomes part of routine care:

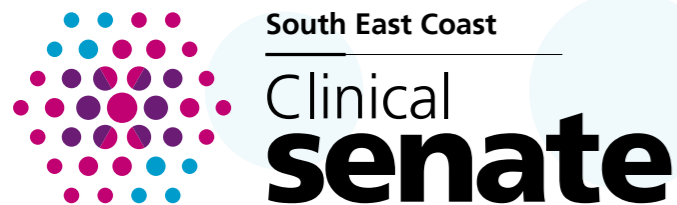
- all professionals providing care for patients need to be clear and agree responsibility for having ACP discussions across teams and organisations.
- education and training of healthcare professionals needs to be implemented about the importance of, and approach to, ACP and end-of-life care.
- awareness needs to be raised amongst the general public, patient support organisations and the voluntary sector about the benefits and how to confidently initiate ACP discussions themselves.

The SECCS identifies the need for much better coordination of the work of commissioners, GPs, hospital staff, care homes domiciliary carers as well as community, patient support and voluntary sector organisations in the creation and delivery of these plans.

The SECCS concludes that there is a real opportunity to increase the use of ACP to ensure that it is fully integrated into high quality, patient-centred care across Kent, Surrey and Sussex, and nationally.



Advance Care Planning: a guide



The South East Coast Clinical Senate (SECCS) considers that a radical change is needed to provide high quality care for people approaching the end of their lives. Advance Care Planning (ACP) should be far more widely used as an important part of this.

For people living in Kent, Surrey and Sussex this is particularly important. There is a high proportion of elderly people, many with dementia or other conditions who risk falling seriously ill with impaired capacity. ACP is also relevant to people who undertake high risk activities such as extreme sports and those who may develop health conditions that could impair their mental capacity, including children and young people.

What is advance care planning?

Advance Care Planning (ACP) is the voluntary process of discussion to help a person decide on their future care while they have the mental capacity to do so.

ACP is far more than a record of a person's preferences towards the end of their life. They enable the development of a care plan acceptable to the person, their family, and carers, and to health and social care professionals.

The use of ACPs spans many different conditions, professions and organisations, as well as being something of relevance to the public at large.

What are the benefits of ACP?

An ACP discussion allows everyone to focus on good communication, so that a care plan can be developed, which really reflects the wishes of the individual concerned and allows family, carers and professionals to be confident that they will be carrying out the individual's wishes should the person concerned lose mental capacity. In particular:

- Patients and carers value ACP. They make conversations possible about treatment plans, symptom control, prognosis and the choices that the patient and their families need to make.
- There is evidence that discussing ACP with patients aged 65 and over increases their satisfaction with the care they receive.
- People report several reasons for wishing to have ACP discussions, including not wanting to be a burden on others and addressing their fears and anxieties regarding the end of their lives.
- ACP can improve a person's quality of life by creating a mutual understanding, enhancing openness and giving hope and confidence about the future.

Who should start the process of ACP, and when?

- ACP can be started by anyone at any time: the patient, their family, carer or a healthcare professional. Patient support groups and organisations, and the voluntary sector can all help to raise awareness in the community.
- The timing of conversations may prove challenging, especially for patients with conditions that can be stable for many years only to deteriorate suddenly. ACP therefore needs to be approached early – and, of course, sensitively – when the patient is well enough to participate. It should become much more a part of routine care.
- For children with life-limiting conditions, ACP is needed to improve care, avoid potentially harmful interventions and deliver choice to them and their families.
- ACP conversations are potentially challenging, sensitive and complex and need training, time and skill to do well.

