

What is pediatric Advance Care Planning (pACP)?

- pACP is a lifelong process of reflection and communication to identify values, wishes and beliefs in relation to the kind of health and/or personal care a child, or parent may want for their child, to guide future healthcare decisions at times of great uncertainty.
- In pediatrics, this also includes considering the child's ability to understand, participate and make specific decisions in regards to their care.
- Pediatric ACP (pACP) involves the concept of parallel planning – planning for both the life of the child while also planning for deterioration/death to allow for the child's full potential. This primes the mobilization of services and healthcare professionals when necessary.
- An Advance Care Plan may at times look like an anticipatory care plan – laying out actions to be taken if or when a child's illness is unstable or deteriorates or they develop life threatening complications due to their illness.

Why are ACP/Goals of Care (GOC) conversations important?

- pACP is recognized in the literature to increase children's (when applicable) and parents' capacity to anticipate decisions, support family coping, provide peace of mind, increase sense of control and reduce suffering.
 - A child/family have the ability to plan anticipated healthcare decisions when ACP/GOC conversations happen early, regularly and routinely across a child's illness trajectory, which can often facilitate adaptation to illness realities and improve communication between child/family and healthcare team.
- ACP/GOC conversations with children/families have shown to impact satisfaction of care and overall quality of life of the child.

How should these discussions take place?

- Strong evidence suggests holding conversations in a step-by-step process is preferred along with a gradual and sensitive family-centred approach with shared decision making.
- All ACP/GOC discussions should include the elements/concepts of asking permission, exploring understanding and information needs, active listening, responding to emotions, sharing prognosis, and making recommendations that incorporate parents' wishes/values/understandings.
- A secondary goal of these conversations is to build/promote trust and safety with a child/family.
- CPCH adapted the adult Serious Illness Conversation Guide process to use with parents of children with serious illness. Adapting the guide recognizes family-centered language, parents/guardians as the primary decision-makers, flexibility for a child's developmental stage and consideration surrounding the difficulty of prognostication in children with rare diseases. The Serious Illness Conversation for Pediatrics resources can be found [here](#).

CPCH provides support, mentorship and training for principles of ACP/GOC conversations based in SICG-Peds. **For clinical support or mentorship for ACP/GOC conversations for a child/family during regular weekday hours call 604-742-3478 to speak with an CP Advanced Practice Nurse or Physician. For urgent or after hours support call 604-3475.**

CANUCK PLACE CHILDREN'S HOSPICE (CPCH) ADVANCE CARE PLANNING INFO SHEET

When should conversations occur? How often should ACP/GOC be reviewed/revisited?

- Some conversations are formal appointments or interviews with families. Many healthcare clinicians will have these conversations during moments of care – the conversations may emerge as informal and unplanned.
- At CPCH, planned conversations occur annually/regularly and normalized as routine to the care of the child with a serious illness on the CPCH program.
- Planned conversations should occur as needed. The following delineate situations that may be prompts to revisit GOC:
 - New diagnosis
 - Serious illness progresses/ difficult symptoms
 - Symptoms become unmanageable
 - Escalation of treatment
 - New treatments become available
 - Changes in family/child capacity/coping
 - Requested by the family
- Canuck Place will assess the need to revisit goals of care with a child/family if requested from other healthcare team (e.g., ICU). Assessing the need for a conversation does not necessarily mean goals will be revisited with the family; however, a CPCH team member may need to meet with the child/family's healthcare team to clarify issues and address concerns.

Where should conversations occur?

- When possible, conversations are best conducted in a comfortable, private setting OR a setting that meets the needs of the child/family.

Who should attend these conversations?

- It is not necessary to have every involved healthcare clinician in the room during these conversations. These conversations could occur over a period of time and other clinicians can be included as needed.
- Consider including the people that family identify as being integral to shared decision-making and active participants in the care of the child. When possible, the child should be included and their wishes should always be considered.