Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

Subject -Disability Level 1 skills / knowledge **Expected behaviour for case study**

Case study

Jose is 26 years old and has muscular dystrophy. Jose lives with his parents and younger brother. His parents have been his long-term carers. Jose was admitted to hospital with abdominal pain and suspected pancreatitis. Jose is non-invasive ventilator dependent and has a PEG tube for nutrition. Jose wants to discuss his care preferences, as there has been discussion about interventions for Jose's pancreatitis. Jose is concerned that his mother may not be able to follow his preferences for care, as she wants him to stay alive with all interventions.

Law	Explains that a person is presumed to have decision-making capacity unless there is reason to suggest otherwise	HCP explores Jose's understanding of his health status and why he was admitted to hospital. HCP encourages Jose to continue advance care planning discussions post discharge with his GP and community care team.
	Recognises and locates relevant advance care planning documents and identifies the person's substitute decision-maker	HCP is aware of ACP and SDM related documents for own area and can locate these for Jose.
	Demonstrates appropriate processes to add an advance care planning document alerts on local systems	HCP is aware of how to include the discussions and if completed any ACP alerts in the local system.
Communication - with the person / family / carers	Explains advance care planning and can provide general information about it	Jose initiates a conversation with the healthcare professional (HCP) about appointing a substitute decision-maker (SDM) and wants to know if he can only nominate one person. HCP is aware of what the SDM laws are for where he works and can provide a valid answer.
	Recognises trigger factors where advance care planning may assist a person and can refer to others	HCP recognises Jose's health status and admission to hospital are trigger points for advance care planning (ACP) discussions. HCP shares with the treating team Jose's desire to discuss ACP and consideration of Jose's preferences when treatment decisions are considered.
	Initiates an advance care planning discussion	HCP identifies that an early advance care planning discussion with Jose is appropriate.
	Reflects on their personal values and preferences	HCP recognises that the perception of quality is individual and reflects on their values that would

	and can differentiate between these and consumer agenda	influence their own decision-making. HCP is able to focus on Jose who is accepting of his quality of life, even though he has many physical restrictions.
Communication - with the team	Identifies the contribution of all health professionals and care workers in a person's advance care planning discussions	HCP recognises that there are many people involved in Jose's care including his parents, community care, GP, respiratory team, cardiac team, GIT, dietitians, physio and OT etc. HCP recognises that Jose may want to continue advance care planning discussions with his other team members such as his GP.
	Recognises and discusses when treatment interventions may not match stated values and preferences for care	HCP can discuss with Jose how an advance care plan and appointing a SDM can provide a guide for decision-making if he cannot speak for himself and that this may reassure Jose.
	Is aware of processes to receive, store and share advance care planning documents	HCP documents the discussion and encourages Jose to speak to his parents and the healthcare team.
Ethics	Recognises that there may be different perspectives between the goal of the person, the substitute decision-maker and the healthcare team	HCP recognises the potential for differing perspectives between the family, Jose and the treating team. HCP encourages Jose to speak to his family about his preferences.
	Explains to the person with sufficient capacity that they can guide the healthcare team regarding interventions	HCP explains to Jose the advantages of ACP and appointing an SDM, if he is not able to speak for himself.
Communication - over time	Identifies what the person wants to achieve from the advance care planning discussion	HCP identifies the need for Jose and his parents to discuss Jose's preferences for care and documents this discussion.
	Recognises triggers to review advance care planning documents	HCP identifies trigger to consider ACP and appointing an SDM include: Jose's admission to hospital; his co-morbidities; Jose's desire to clarify his preferences for care.
	Informs the team of the existence of any advance care planning documents	HCP identifies to the team that there is no SDM appointed and recommends the healthcare team continue to have an ACP discussion with Jose.
	Recognises the loss of decision-making capacity	HCP recognises that Jose is currently able to speak for himself but given the triggers, Jose may want

and discusses this with the healthcare team	to consider documenting his preferences.
---	--

Points of assessment / discussion	Jose's capacity to make an ACD, managing potential family conflict, acceptance of Jose's choice to choose between treatment options and appoint an SDM.
Method of assessment	MCQs regarding role of SDM and appointing one SDM, how to manage a family meeting. Reflection regarding choice of intervention over quality.

(May, 2022)