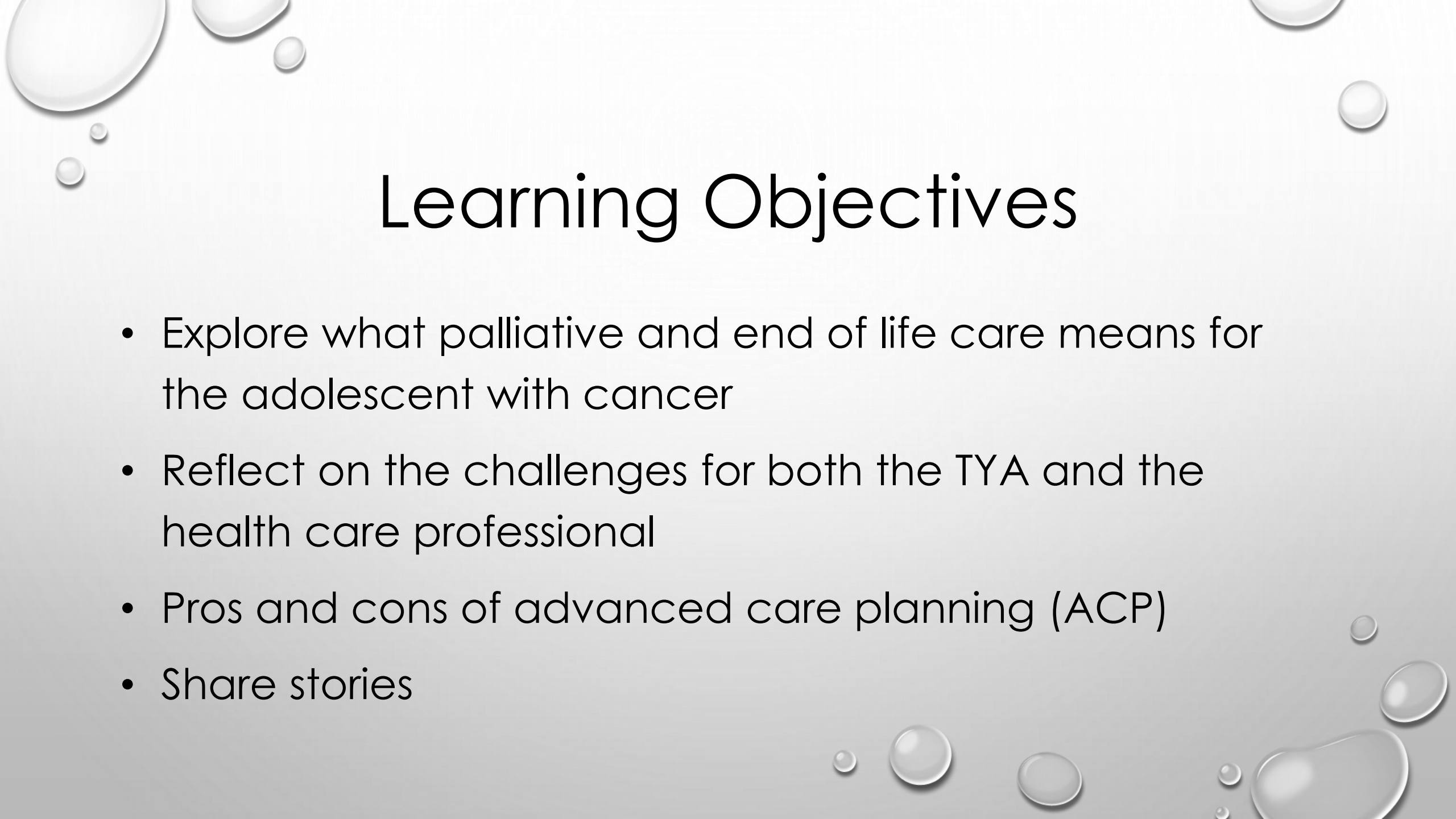




# Palliative and End of Life Care for TYAs

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# Learning Objectives

- Explore what palliative and end of life care means for the adolescent with cancer
- Reflect on the challenges for both the TYA and the health care professional
- Pros and cons of advanced care planning (ACP)
- Share stories

# Effective Adolescent Care

*“The key value of TYA care is to allow the young person to mature through their illness, developing coping strategies and a sense of self”* – TCT nurse group 2012

- Maintain normality
- Preserve and nurture identity
- Promote wellbeing

# Scenario

J, 18 and a half. First diagnosed at 14 with osteosarcoma and treated in BCH.

Relapsed at 16, started treatment in BHOC, still under the paediatric oncology team but with a TYA keyworker. At 17 became palliative, had radiotherapy and started on a phase 1 trial in Birmingham. At 18 came off trial as relapsed disease had progressed, symptom control and quality of life became priority. Referred to the Supportive and Palliative Care Team and Psychology, and St Peter's Hospice for community support.

Became increasingly SOB with uncontrolled pain. Oxygen set up at home, but days later brought into hospital again (Hospice was full) but no appropriate bed available. Nursed in a side room on D703 and died (peacefully) hours later. Family did not expect him to die, J thought he had around a year left. He had not made any plans, but had had the start of a meaningful EOL discussion with psychologist - but did not want to continue.

What are the challenges for J, his family and the health care team?

# Challenges for the Palliative Adolescent

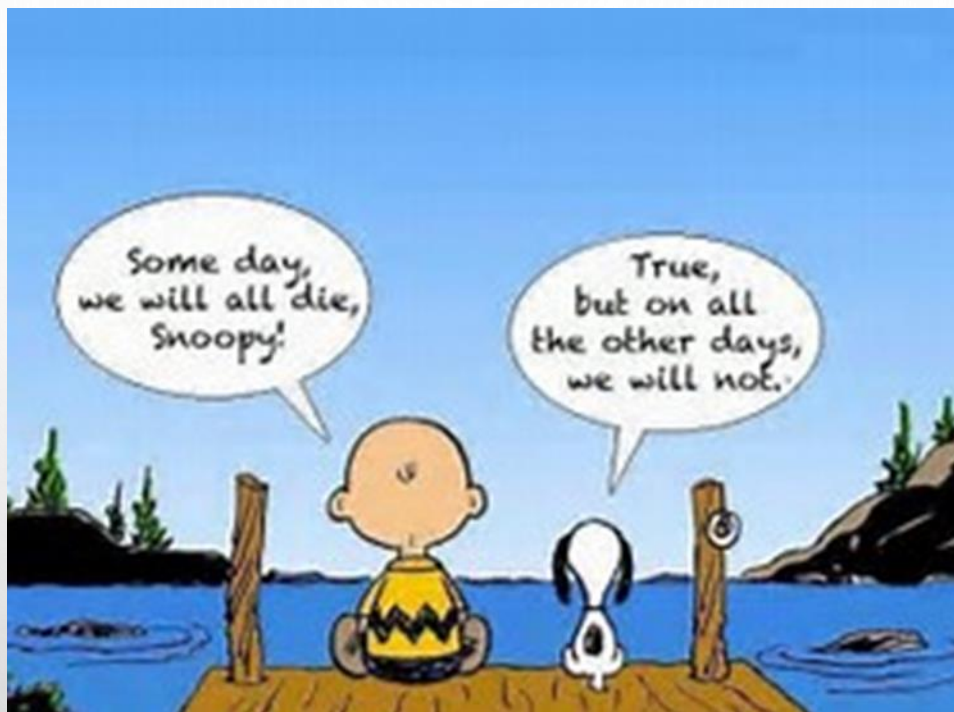
- Concurrent transitions, differing approaches
- The emergence of self-identity and future possibilities
- Focus on legacy, what can they achieve in the time they have left?
- Feelings of abandonment and uncertainty when curative treatment stops
- End of life conversations are difficult to initiate by adolescents
- Place of death

# Advanced Care Planning (ACP)

- Improves communication, social support, autonomy and emotional wellbeing and reduces stress, anxiety and depression (Smith 2017)
- Facilitates the transition between curative to palliative care (Wiener, Pao and Zadeh 2015)
- Prepares patients and their families for future end of life care decisions that are in line with their values, goals and preferences (Sudore et al 2017)

# Challenges of ACP

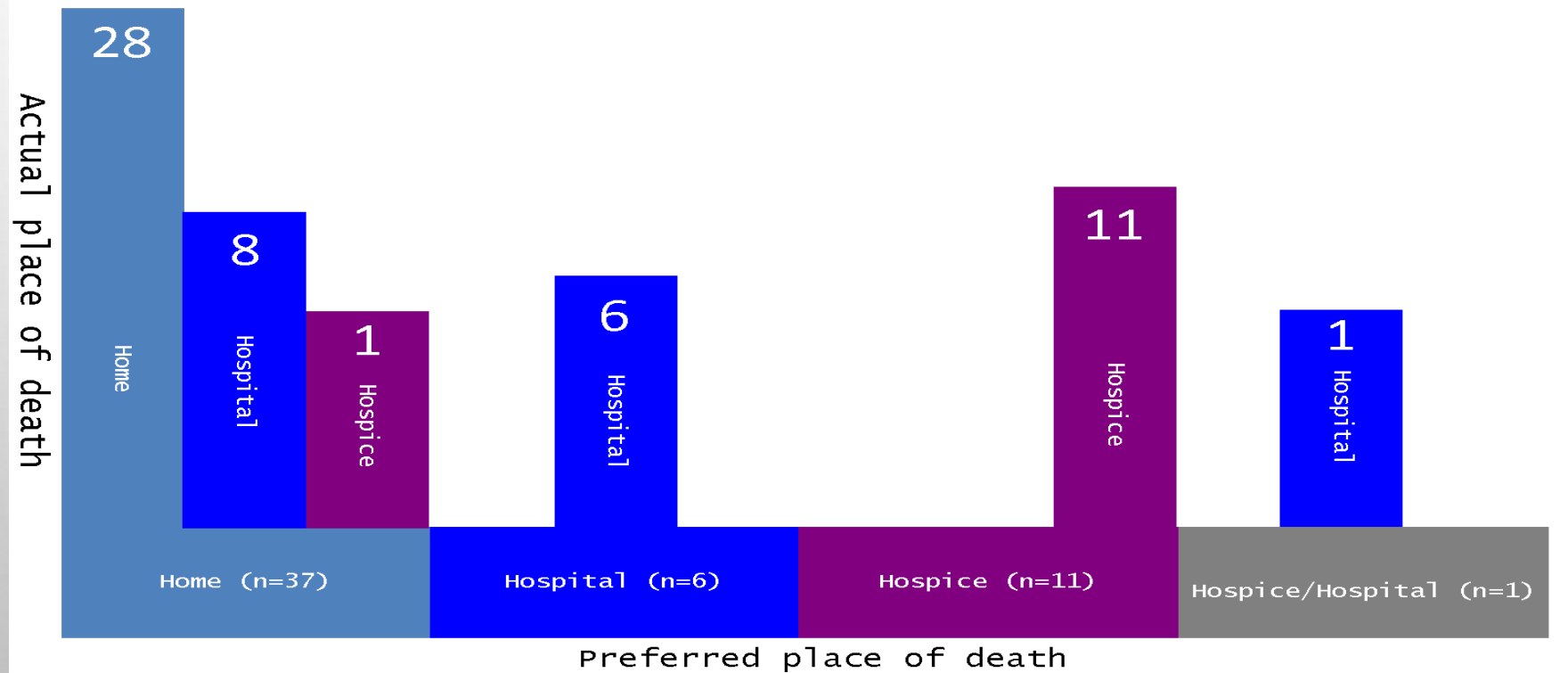
- TYA engaging in conversation at differing levels of emotional acceptance
- Late identification of incurable disease and missed opportunities – EOL in acute and critical care settings
- TYA changing of care preferences, not communicating changes to significant others
- HCP fear of causing loss of hope, and of intense emotions
- HCP lack of training, and of therapeutic relationship with patient and family
- HCP and TYA focus on cure can mean missed opportunities
- HCP lacking the skill of balancing hope with possibility of death





# Place of Death

Information on preferred and actual place of death was available for 55 (63%) patients



# What Do TYAs Value in a Healthcare Setting?

- Privacy and a sense of control
- Socialising and distraction
- Peer support plays a more significant role in adolescence
- Relaxed routine that supports sleep and rest, and discourages the patient label
- Therapeutic relationship with staff members

# Things to ask yourself.....

- How far has the TYA transitioned away from their childhood and into adulthood, and are there any parental tensions?
- How far have they transitioned from curative to palliative care?
- How loud is the TYA's voice in ACP or in EOL care? Should it be louder?
- If they were not dying what would the TYA be doing with their time, and how can you facilitate them doing it?

# TYA Team Stories

- Arranging last minute weddings
- Planning funerals, making goodbye videos
- Death party planning
- Supporting sexual needs
- Supporting bucket lists, wishes and freebies (travelling against medical advice)
- Support through pregnancy
- Support in re-uniting with parents
- Support in keeping parents away

# References and Resources

Gardiner et al ***Exploring the transition from curative care to palliative care: a systematic review of the literature***. BMJ Supportive and Palliative Care 2015, 5.

Lotz et al “***Hope for the best, prepare for the worst***”: A qualitative interview study on parents’ needs and fears in paediatric advance care planning. Palliative Medicine (31) 8. 2017.

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Wiener et al ***Threading the Cloak: palliative care education for care providers of adolescents and young adults with cancer***. Clinical Oncology in Adolescents and Young Adults 2015, 5.

[www.teenagecancertrust.org/sites/default/files/blueprintofcare\\_2ndedition.pdf](http://www.teenagecancertrust.org/sites/default/files/blueprintofcare_2ndedition.pdf)

[www.dyingmatters.org](http://www.dyingmatters.org) and @DyingMatters

[www.deadsocial.org](http://www.deadsocial.org) and @DeadSocial

[www.lwdwtraining.uk](http://www.lwdwtraining.uk) and @livingwelldying

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