



Teenagers and
Young
Adults with
Cancer



Communicating with teenagers and young adults with cancer

TYAC Good Practice Guide for health professionals

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Background

Communication is a fundamental theme throughout the totality of the cancer trajectory. It is increasingly recognised that teenagers and young adults with cancer [TYAs] have experiences and communication needs that differ significantly from those of younger children and older adults. Communication with TYAs is critically important however, for healthcare professionals [HCPs] learning and experience is often incidental, with limited opportunities for formal postgraduate education.¹

Effective communication is critical to reduce anxiety and promote adherence to treatment in TYAs as they find it challenging to adhere to treatment due to the severity of their illness and symptoms.²⁻⁴ If young people are not heard and understood they can be labelled as difficult or a challenge which inhibits shared decision making and undoubtedly affects their future care.⁵

Importance

Current research suggests that HCPs acknowledge and find communicating with TYAs as different and difficult.⁶⁻⁸ The reasons for this are likely multifactorial including the developmental and transitional nature of adolescence. An under researched factor is triadic communication – the presence of a third person in a conversation; this is an important consideration with 87% of young people attending appointments with another person.⁹ Communication is considered a core skill for professionals who care for TYAs. Despite this, training is ad hoc and is mostly for either doctors or nurses with only a minority of training being interprofessional.^{7,8} This is a considerable challenge given the multidisciplinary nature of TYA cancer care; training and education continues to be a priority.¹⁰ The importance of effective communication aligns with the priorities of service users and health and research organisations nationally.¹¹⁻¹³

Aim

This guideline aims to equip HCPs with tools to assist in effectively assessing TYAs' preferences and engaging them in communication at the level they desire.

Evidence for this guideline

The recommendations in this guideline were formed by combining the findings from a scoping review of the literature and a questionnaire sent to teenagers and young adults with cancer:

- The scoping review examined all papers published in the last 10 years looking at communication with young people.
- The questionnaire aimed to add to this data by specifically asking young people about their experiences of communication.

We have found themes related to young people, supporters (the parents/carers/siblings/partners or other people important to and present with the young person), healthcare professionals across the literature and from patient responses, and these are detailed below.

Teenagers and young adults with cancer

1. **Being seen as a person:** young people needed to feel that those caring for them see them as a person with individual wants and needs beyond their diagnosis.
2. **Involvement across the cancer experience:** involvement varied over time, generally young people were less involved closer to diagnosis, but become more involved as they adapted to their diagnosis and new normal.
3. **Personal preference:** there is no 'one size fits all' approach. Young people have their own experiences and preferences for communication which healthcare professionals need to adapt to. This is not static and varies based on context and changes over time.
4. **Emotions:** young people recognised how emotions affected their ability to communicate; this was particularly evident at diagnosis.

Supporters

1. **Mutual protectionism:** young people may want to protect the supporters with them from difficult emotions or challenging subjects and vice versa.
2. **Enablement:** supporters are a central tenet of TYA cancer care. They act as a support system and can occupy several roles, including translating medical language in a way the young person can understand and asking questions on the young person's behalf.
3. **Gatekeeping:** parents may filter information, which is passed on to the young person; this was particularly problematic when young people are present for discussions.
4. **Parental responsibility/legality:** parents may attempt to override decisions of the young person where they don't agree with the choice made by the young person.

Healthcare professionals

1. **Trust:** young people need to feel they can trust healthcare professionals and this facilitates engagement with treatment. A key element of trust is open and honest communication, directed at the young person.
2. **Rapport:** by developing a relationship with young people, healthcare professionals are able to engage them. A key part of this is understanding the young person's psychosocial context. Young people like continuity of healthcare professionals where possible.
3. **Enabling involvement:** healthcare professionals play a central role to facilitate engagement of the young person but should do so at the level they want.
4. **Developmentally appropriate language:** young people are often healthcare naïve and may not understand complex language or medical jargon. HCPs must communicate in a way that the young people can understand, being mindful of developmentally-appropriate healthcare principles, but should not be patronising as young people often feel like they are spoken to like a child.

Impact of effective and ineffective communication



Questionnaire results

The survey aimed to specifically ask young people about their experiences of communication with healthcare professionals. We had 24 survey respondents from England, Wales, Scotland, and Northern Ireland and across various haematological and solid tumour sites.

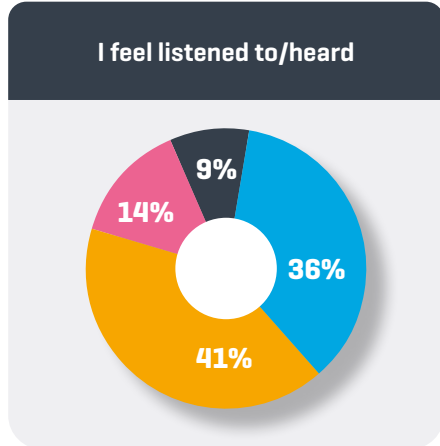
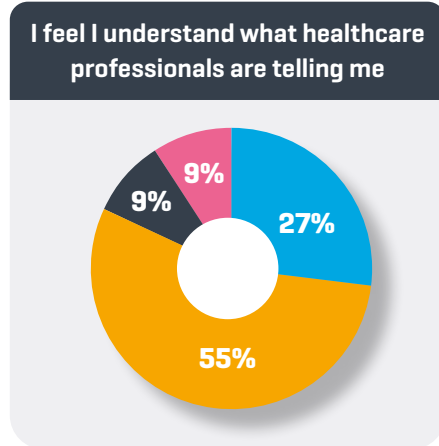
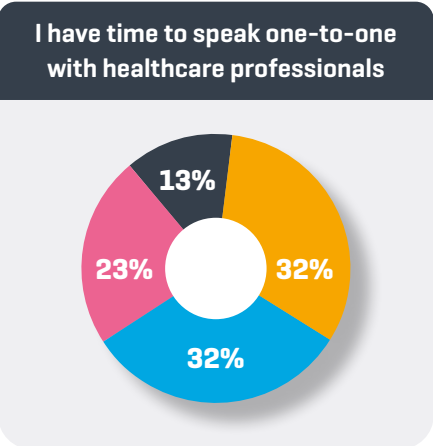
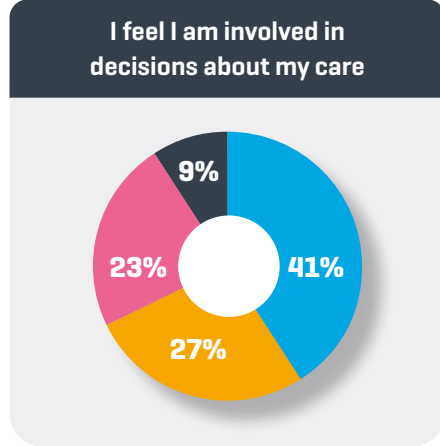
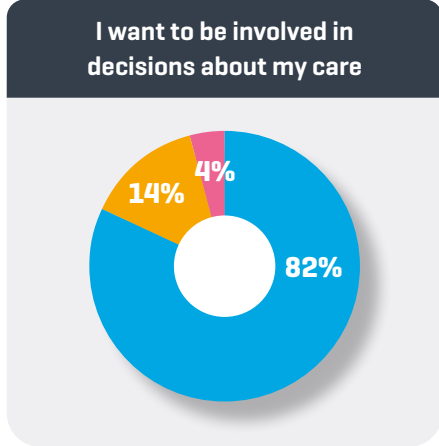
Young people were with parents [59%], alone [18%] or with a partner [23%] for healthcare conversations.

Table 1: Participant characteristics

Age at diagnosis years - mean (range): 19.6 (13-24)	
Diagnosis - number [%]	Ethnicity
Leukaemia - 9 [37.5]	White - 22 [91.7]
Lymphoma - 5 [20.8]	Not disclosed - 2 [8.3]
Brain - 2 [8.3]	
Sarcoma - 4 [16.7]	
Testicular - 4 [16.7]	
Gender - number [%]	Sexuality - number [%]
Male - 8 [33.3]	Heterosexual - 16 [66.7]
Female - 13 [54.1]	Gay/lesbian - 1 [4.2]
Non-binary - 1 [4.2]	Bisexual - 3 [12.5]
Not disclosed - 2 [8.3]	Asexual - 1 [4.2]
	Not disclosed - 2 [8.3]

My experiences

● Never
 ● Rarely
 ● Sometimes
 ● Often
 ● Always



Data from the questionnaire showed that all of the young people want time to speak one-to-one with healthcare professionals. The majority wanted to be involved in decisions regarding their care always (82%). Despite this, only 41% felt they were 'always' involved in decisions about their care. The majority of respondents had one-to-one time with a healthcare professional at least sometimes. The majority of respondents understood what was being said to them most of the time, and felt listened to/heard. However, notably there was variation in both the preferences and experiences of young people, which fits with the findings from the literature review.

Key quotes

Below are some salient quotes from the questionnaire.

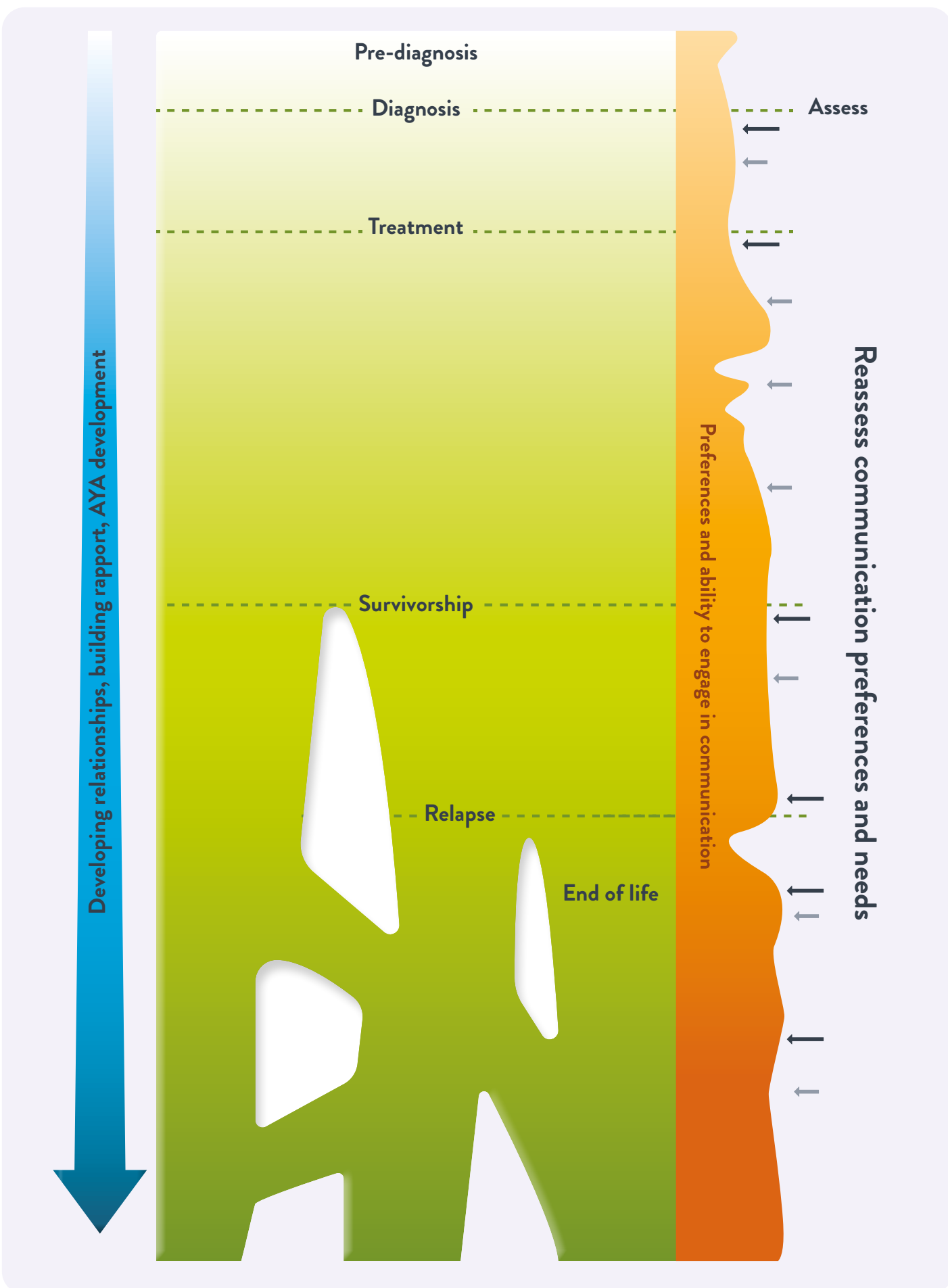
"I got told I had 'the good cancer' and that I was 'lucky' multiple times throughout my treatment which really hurt because I was going through so much, losing my fertility, my hair, my social life, last school year and so much more and it felt minimised by comments like this, made me feel like I was dramatic for finding it difficult."

"Asking questions and allowing me to ask questions. Being polite and positive. Asking if I would like to talk in private if it's a sensitive matter."

"It was patient, taking time to answer all my questions without making me feel rushed. They were friendly and spoke to me as though I was equal and didn't talk down to me."

"It was clear, direct, and realistic. They brought me back from unrealistic expectations when appropriate, and have encouraged my realistic but ambitious goals."

Figure 1 - Visual representation of a young person's cancer experience over time



The figure is a visual representation of the cancer experience of a young person over time. They move through multiple phases and the experience spans multiple psychological, social, and developmental transitions. The bottom of the figure demonstrates the divergent and interconnected post-treatment phases which include survivorship, relapse, and end of life care. Over this time, it is crucial that healthcare professionals establish, build and maintain rapport to facilitate effective communication across this experience (shown by the arrow on the left-hand side). The [orange] axis on the right represents the potential fluctuations in agency of the young person and/or their desire to be involved in treatment related communication.

This may be for several factors such as emotional or physical deterioration, increasing knowledge and experience with healthcare systems, or established relationships with healthcare professionals. The right-hand bar and arrows represent the need to assess and reassess the communication preferences throughout this experience. This is pertinent both when entering a new phase of care (black arrows) and during a phase of care (grey arrows).

Practice recommendations for clinicians

What young people want – communication objectives	How to achieve it – effective communication skills
Initiating the interview	
A trusting relationship with healthcare professionals	<ul style="list-style-type: none"> • Be professional, friendly, warm and open, and smile. • Check in often and offer contact details. • Be empathic, acknowledge, and do not dismiss the young person’s situation. • Show willingness to help and problem solve.
To be treated like a person and not just focus on cancer	<ul style="list-style-type: none"> • Take a genuine interest in the young person’s life outside of their cancer diagnosis.
To be heard and understood	<ul style="list-style-type: none"> • Look at the young person and talk directly to them. Take your time to build a relationship. • If someone attends with them, ask the young people to introduce their supporter(s).
Triadic communication	
To receive help from supporters	<ul style="list-style-type: none"> • Check the young person is happy for the supporter to be present and be clear on their role in the communication encounter. • Use internal summary and signpost (summarise what has been said by one party and reflect this back to the other person present to get their opinion) to get the young person’s perspective on questions or observations from the supporter. • Ensure everyone’s agendas are heard and met where possible.
To not be talked at like a child	<ul style="list-style-type: none"> • Speak to the young person at a developmentally appropriate level and check for understanding often. • Do not refer to them as a child, or kid.

Time alone with healthcare professionals	<ul style="list-style-type: none"> • Signpost that time alone is offered and routine practice. • Always offer time alone without the presence of supporters during every encounter and normalise the process.
Gathering information	
Listened to	<ul style="list-style-type: none"> • Listen attentively. • Maintain eye contact, be vigilant for verbal and non-verbal cues. • If there are clues that something isn't heard or the young person looks unsure, explore, problem solve and amend the approach.
Individualised care	<ul style="list-style-type: none"> • Find out what motivates them and what is important in their life. • Do not make any assumptions [e.g. about home situation, gender, sexuality]. If you are not sure just ask. • Discuss treatment plans with the young person and if conflict arises try to agree a compromise where possible. • Be aware of additional needs, for example hearing and sight impairments, neurodiversity, minority groups, low literacy, memory impairment [particularly whilst receiving chemotherapy], cultural considerations.
Explanation and planning	
To understand what is happening	<ul style="list-style-type: none"> • Use developmentally appropriate language. • Give the information in small parts and check the young person understands before moving on [chunking and checking]. • Encourage the young person to ask questions.
Honest information	<ul style="list-style-type: none"> • Find out how much information the young person wants, at that point in time [some want a little, some a lot, others somewhere in between]. • When giving information be clear, direct, and honest [however difficult].
Shared decision making	
To be involved in decisions about their care	<ul style="list-style-type: none"> • Ask how involved the young person wants to be in the decision. • Who else do they want involved in the decision?
Closing	
Know what happens next	<ul style="list-style-type: none"> • Be clear to end the communication encounter with a follow up plan. • Encourage questions. • Check the young person understands. • Give contact details.

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Teenagers and Young Adults with Cancer [TYAC] is the UK's professional association for those who treat and care for teenagers and young adults with cancer. Our strength lies in our knowledge and understanding that teenagers and young adults have different and specific needs to children and older adults, and require age-appropriate care.

By providing information on good practice and new developments, training and support to our members, and through funding and supporting research into teenage and young adult cancer, we aim to improve the quality of life and likelihood of survival for young people with cancer.

Our purpose:

- To be the leading national platform for influence and progress in teenage and young adult cancer treatment and care.
- To support and empower our members through education, awareness, research and knowledge.
- To seamlessly bridge the gap between child and adult cancer care for all TYA patients.

We are working hard to break down barriers and fight for change for all teenagers and young adults with cancer.

Join TYAC as a professional member: www.tyac.org.uk/membership/become-a-member

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