

# Teenage and Young Adult Cancer Youth Advisory Forum

## Young Person's Principles of Communication



### 1. Take time to build a relationship with us

- Find out who we are, what we like and what's important to us. We are more likely to engage with you and trust you, if we feel like we're being treated as individuals
- Have a conversation with us about where we want to be treated, fertility options and all of the big things that will make a difference to us long-term

### 2. Ensure that the style of communication is preferable, and tailored, to us

- Sometimes, a text message is fine, especially if it's confirming appointment times or quickly answering questions
- Geographical issues may mean that post is delayed (or not delivered at all), so this may not always be the best way to share information
- Ask if we want to be spoken to directly, rather than speaking to our parents or carers, especially during clinic or telephone appointments
- Face-to-face is preferable, as this helps us with visual cues and body language during conversations
- If we have appointments for follow-up, it would be useful to be offered telephone check-ins, rather than travelling a long distance for a short appointment time

### 4. Be transparent with us and always try to give us honest answers to our questions

- We understand that there is a balance between providing hard facts and being sympathetic or apologetic, especially for conversations around diagnosis or prognosis. Always try to give us the important information that we need – this may become easier once we build a relationship with you, as you will know what our preferences are
- If treatment hasn't gone to plan, or if the plan has changed, have an honest conversation with us. We would rather know the facts so that we can process what's going on

### 6. Keep us involved in decisions around our care and treatment plans

- It is important for us to understand our treatment and any side effects that we will have. We would be happy to have conversations around place of care, changes or benefits in treatment plans, fertility preservation and clinical trials. Help us to understand our care and any long-term effects as a result of treatment
- Give us the option to be treated in a principal treatment centre, or closer to home, if that is the best option or what we would prefer

### 8. Always use face to face communication for big news, if possible

- We understand that processes changed through COVID, and that telephone or virtual appointments replaced face-to-face appointments. Although it is useful to have various options for communication, if we are being contacted for a diagnosis talk or to be told major news, face-to-face communication is preferable

### 9. Avoid apologetic language (it clouds the results we are being given)

- We understand that diagnosing a young person with cancer is difficult, especially if the plan isn't quite clear yet. When you do tell us our diagnosis, or if we have any big conversations about treatment or prognosis, be honest and give us the facts, if that's what we want. Be kind, honest and open with us

### 3. Use language that we understand and be aware of your choice of wording – medical jargon can become confusing and overwhelming

- Medical jargon can create a barrier between us and our clinical teams. The unknown words or terms can create further fear or confusion, so be as clear as you can in language that we understand
- Be aware of the language used both directly and indirectly when young people are present

### 5. Treat us as young adults, rather than focusing on our age and perceived maturity

- We are often more resilient than you realise – although we are young adults, we would like to be treated as capable, competent and be given the opportunity to understand exactly what is happening
- Understand that we need holistic care. Our treatment is important but so is our education, career and our relationships. We may also be worried about responsibilities such as; housing, rent, mortgages, finance payments, child maintenance, plus many more factors that may impact our emotional wellbeing and ability to remain resilient

### 7. Give us a key point of contact for questions and any concerns

- It's really important for us to have a medical point of contact between treatment sessions or appointments. Often, we have questions or concerns, but may not know who to approach. Having a Key Worker would be a brilliant resource for us and would make our treatment journey much more manageable and straight forward

### 10. If delivering news over the phone, ensure we are prepared and have support around us

- If any telephone appointments are scheduled, ensure that we are prepared and given a time and date for the call. If the telephone call is to deliver 'big' news, such as diagnosis, treatment plan, prognosis or changes in our care, please give us an idea of this beforehand. This will enable us to prepare, be somewhere safe and quiet, and to have people around us to provide support



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