



# Communicating complex information on personalised therapies

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## How to explain

- How complex therapies work
- How the drugs only work on some people but not all
- Potential harms and benefits in a way people understand
- How to explain trial data which is limited to a small number of patients and the safety profile is unclear

## How to achieve

- Shared decision making values based practice is achieved for all

## The '4 Ps'

Personalised medicine is sometimes conceptualised as a '4 P' model:

**Predictive** –  
determining the risk/susceptibility and treatment response

**Preventive** –  
allowing early intervention to prevent the disease altogether

**Personalised** –  
according to the genetic make-up of the person and their disease

**Participatory** –  
involving the patient in decisions on prevention or treatment

Source: adapted from [Future of Cancer Care](#), BCRF.

Our aim is to encourage patients to make informed decisions by giving them information to improve their understanding and knowledge and to empower them.

So in terms of producing written information we have a duty to:

- Evaluate the information we have to hand and interpret it to pass on to our patients so that they understand it.
- Be honest when discussing information and acknowledge that we may not have all of the facts but we can share them when we do have them.



**In our desire to appear thorough  
we can give lots of information  
and believe that we have communicated effectively**

**Information in itself is not communication**

## Questions to consider:

1. How do we know that a patient wants information?
2. How do we know what patients do with that information?
3. How do we know that the patient understands what we are telling them?
4. How do we know that the patient wants to be involved in a shared decision making process?



# We need to pay attention to the onward journey of communication



1. **Emotional cognition plays a significant part in how patients are able to process information.**

## **Open awareness context:**

**suspended:** patients are likely to receive the same information on various occasions but will not accept information if they feel it is overly pessimistic

**uncertain:** information will be disregarded if it perceived to be negative, in favour of holding on to the belief of a hopeful outcome

**Active:** people appear fully informed and understanding and will act on the information they receive to help them make informed choices

## 2. Don't assume the patient wants to receive all of the information you wish to give them find out what their prior understanding is and their agenda

### ➤ **Organize explanation:** divide into discrete sections, logical sequence

i.e. 'First I want to talk to you about the side effects of your chemotherapy and then discuss how we will administer it to you.'

### ➤ **Signpost:**

i.e. 'Can we move on to talk about how we need to monitor you whilst you are on treatment?'

### ➤ **Repeat and summarize** to reinforce information

i.e. 'So just to recap, we are going to.....'



- **Use concise, plain language**
  - Avoid jargon
  - Use shorter words and sentences
  - Explain jargon when necessary to use
  
- **Use multiple methods for conveying complex concepts**
  - Visual graphics: diagrams, models, pictures
  - Written instructions
  - Analogies
  
- **SLOW DOWN when talking!!**



### 3. The disclosure of information does not necessarily lead to understanding



Don't take for granted what a patient does or does not understand




How effective is the question: “Do you understand?”

As an alternative use the **‘Teach-back’ method**:

Ask patient to restate their understanding in their own words.

i.e. when you get home, your family will ask you what we have said. What will you tell them?

# 4. We need to ask the patient how involved the patient wants to be in terms of making informed decisions and then facilitate that preference

 **BCCC**  
Better Consultations in Cancer Care

Sheet 1

**YOUR FIRST ONCOLOGY CONSULTATION LEAFLET**

(This is the sheet you use when you first come to Oncology)

Your name \_\_\_\_\_ Signature \_\_\_\_\_ Today's Date \_\_\_\_\_

1. What have you been told so far about your cancer?

2. What would you like to know today about:


a. Your cancer diagnosis:

b. Your prognosis (whether you can be cured or not) (Please tick the relevant box)

- I would like to know the whole picture, including all possibilities, even if this is bad news.
- If I **CANNOT BE CURED** I want to know the basics but I **DO NOT** want the doctor to estimate how long I might live for.

We appreciate these are difficult questions. There is no right or wrong answer and your need for information may change. Your doctor will however, find it helpful to know what you are thinking today.

3. Please consider which of the 5 statements best describes your wish for involvement in treatment related decision-making and tick the relevant box next to it:

A. I prefer to make the decision about which treatment I will receive	<input type="checkbox"/>	
B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion	<input type="checkbox"/>	
C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me	<input type="checkbox"/>	
D. I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion	<input type="checkbox"/>	
E. I prefer to leave all decisions regarding treatment to my doctor	<input type="checkbox"/>	

4. What else would you like to know today?

5. Any other comments

I have rogue cells that need to be dealt with

What treatment to expect and likely side effects

Ticked I would like to know the whole picture

Wants shared decision

When and how long?

## In the follow up consultation:

The patient had already identified his concerns/questions on the leaflet

The doctor addressed his concerns directly

The doctor tried to emphasise that he had a choice and gave him information to help him make that choice

He still wasn't rushed into making a decision at the end of this consultation

**LF: So you didn't feel involved last time?**

**P004: No I felt as if she had made the decision and she was just informing you of what the decision was and I didn't feel as if I was part of the decision making. Whereas I did feel with this doctor that she was offering me options and saying go away and decide what you want to do. So I have got options.**

**LF: And is that what you wanted?**

**P004: Yes because I wanted to be involved in exactly what would happen.....On the first consultation you don't really know what you are going to get, so you don't know what questions you need to be asking. So formulating questions on your second consultation is of more use because you know what you want answers to then.**

## Core Empathic Response Skills

- Non-verbal

## NURSES as a useful mnemonic

- Name the emotion
- Understand the emotion
- Respect the patient
- Support
- Explore
- Sensitivity

# Name the emotion/ Acknowledgement

## Nurse

- Verbally checking the cues with empathic statements
  - **I can see that you are worried that it might be serious**
  - **Seems like things have been difficult...**
  - **Sounds like this illness has been frustrating for you, am I right?**
- If you don't verbalize your impressions, patients won't know you picked up on their feelings!!!

# Understanding/ Acceptance

nUrses

- **Include expression of understanding/concern**
  - **Sounds like you have been having a tough time**
  - **It seems like you just have so many concerns about the treatment**
- **Be careful about saying**
  - **I understand how you feel**
  - **At least....**
  - **It' going to be alright**



# Respect

nuRses

- **Conveying admiration/appreciation for who the patient is and how they cope**
  - You're doing the right thing by getting it checked out and checking this out with your doctor

# Support

nurSes

- **Let the patient know that:**
  - **s/he will not be abandoned**
  - **You and the team are there to help**
  - **You will work with the patient to address problems and concerns**

*'No matter what happens I will be with you throughout your illness'*

*'We will work together to help you manage this'*

# Explore

nursEs

- Elicit any feelings or concerns the patient may have
  - **Can you tell me what you are most worried about?**
  - **How are you feeling about these symptoms?**



# Sensitivity

nurseS

- **Acknowledging and normalising embarrassing and disturbing topics**
  - **I appreciate that it has been difficult to raise with me your concerns about the complexity of this treatment and the risks involved**
  - **These are concerns raised by a number of other patients, so you are not on your own thinking this**

# Consequences of empathic response

- Increased rapport/comfort/trust
- Helps discharge intense emotions > reduced anxiety
- #1 and #2 lead to increased probability of:
  - Patient providing full and accurate information
  - Patient following physician's recommendations
- Increased satisfaction

# Take away points

- Communicating information is challenging but remember to keep it simple
- Don't assume the patient understands what you mean
- Provide information in a logical and sequenced flow that makes sense to the patient (start – middle – end)
- Don't assume that because you have given information the patient will understand it – they won't necessarily and they won't necessarily tell you
- Use communication skills to acknowledge the person as an individual to help you develop rapport and a trusting relationship