Improving communication between hematologists and patients:

Talking about risk, uncertainty, and clinical trials

Professor Dame Lesley Fallowfield
SHORE-C
Brighton and Sussex Medical School, UK

SHORE-C, Sussex Health Outcomes Research & Education in Cancer.
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Disclosures

- **Honoraria:** AstraZeneca, BeiGene, Eisai, Medscape, Pfizer, Veracyte, Exact Sciences
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Complexity of cancer

Better understanding of the genetics underlying molecular biology has facilitated many therapeutic advances in the past decade.

Better diagnostics and more targeted systemic therapies mean that more patients can survive well for longer.

But this is no longer simple to explain.

Patients experiencing emotional turmoil enter a strange new world with esoteric language and concepts.

Slide courtesy of Lesley Fallowfield.

This talk

- General concepts about communication
- Handling risk and uncertainty
- Decision-making
- Talking about trials
- Psycho-social implications of indolent cancer
- Top tips and communication summary

Slide courtesy of Lesley Fallowfield.

General concepts about communication

Benefits of good communication

Improves accuracy of data collection

Helps to draw-out patients' problems

Affects adherence

Influences emotional and physical well-being

Improves the overall experience of care

Reduces risk of litigation and medical complaints

Reduces risk of burnout in HCPs

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Many sad, bad, and complex areas

- Giving the diagnosis and prognosis
- Describing complex tests and treatments
- Talking about clinical trials and randomization
- Handling distressed patients and relatives
- Misinformation from the media or internet
- Transitions from radical to palliative care
- Dealing with unrealistic expectations
- Wanting unavailable novel drugs/treatments

Slide courtesy of Lesley Fallowfield.

Common communication deficiencies

Use of jargon

Talking at, rather than listening; poor tolerance of silence

Incongruent non-verbal behavior

Failure to invite questions or check understanding

No summarizing of next steps

Slide courtesy of Lesley Fallowfield.

Examples of Unhelpful communication strategies

Patient – "Doctor, I'm so worried about my blood cancer getting worse without treatment now."

Subconscious or unrecognized communication behaviors include:

Avoidance

> *"When did you last have your bloods checked?"*

Premature reassurance

> *"I'm sure that won't happen any time soon, so don't worry."*

Cold, professional detachment

> *"Well, it might, unfortunately; I don't have a crystal ball."*

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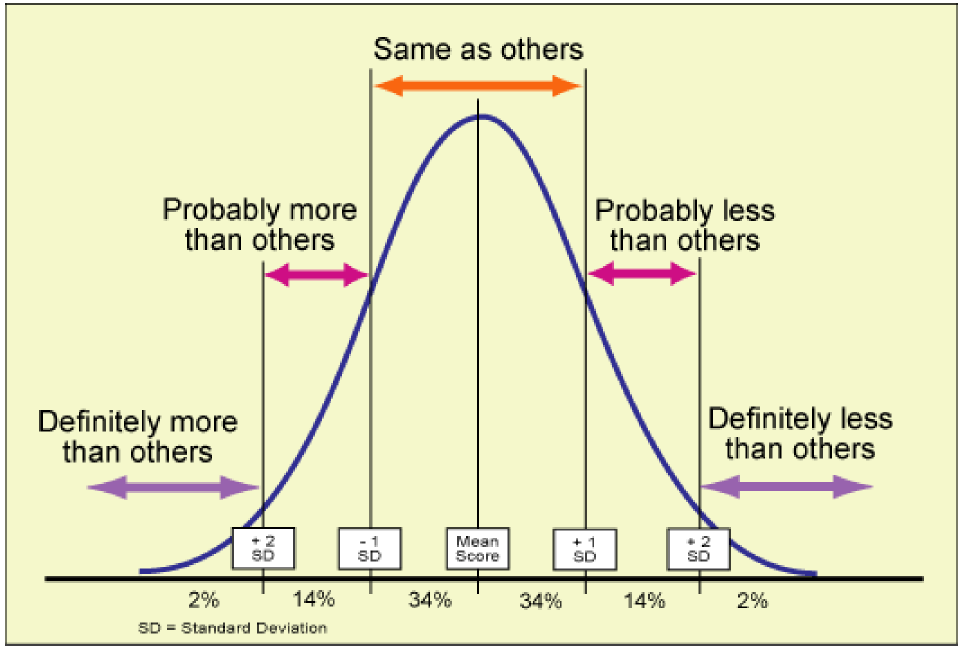
Predicting outcomes



- Arguably harder to prognosticate in hematology than in most other oncology areas, but:
  - Failure, not just unpredictability, as prediction accuracy poor; direction of error (90%) in optimistic direction
  - Better doctor knows patient in length and intensity of contact; more likely to overestimate survival[1] or be honest about prognosis[2]
  - ‘Doing something’ behaviors result, instead of the honest but painful conversations needed[3]

1. Christakis NA *et al. BMJ* 2000; 320 (7233): 469–472. 2. Fallowfield L *et al. Lancet Oncol* 2014; 15 (13): 1423–1424. 3. Fallowfield LJ *et al*. *Support Care Cancer* 2017; 25 (1): 237–244.

Shooting the messenger

"I HATE BEING THE MESSENGER AROUND HERE."

Slide courtesy of Lesley Fallowfield.

Handling risk and uncertainty

Would you walk along a 10 cm wide ledge?

- 1 metre above ground
- 3 metres
- 30 metres

Would you walk along a window ledge 10 cm wide 30 metres above ground to escape rapidly spreading fire in the building?

Risk of falling is the same but likely outcome – harm of falling/benefit of crossing varies

Treatment options with associated side-effects/likely harms versus benefits may be acceptable for some patients if life-saving, less so for others

Discussing risk and uncertainty

Risk is a feature of everything we do in life and medicine

We hate uncertainty, but medicine is an uncertain science

Most facts are merely probabilities defined or refined by repeated hypothesis testing

Huge confusion exists about numbers, and health literacy and numeracy are poor. Much communication takes place against a background of fear and anxiety.

Slide courtesy of Lesley Fallowfield.

Handling uncertainty

Uncertainty is a psycho-noxious experience for anyone

Even more difficult in the context of life-threatening disease to help patients feel reassured

Made worse when doctors’ uncertainty extends to a choice of multiple treatments

Greater alarm if uncertainty involves watchful waiting or surveillance (perceived as no treatment)

Slide courtesy of Lesley Fallowfield.

Tolerance of uncertainty

- Most patients would prefer that the benefits and harms of treatment options were definitive
- Anxious patients have a low tolerance for ambiguity and uncertainty, which provokes fear, perceived vulnerability, and avoidance of decision-making
- How tolerant both HCPs and patients are to uncertainty affects information exchange and decision-making
- Less tolerant HCPs may order more tests or treatments[1]
- Lower tolerance is associated with less likelihood of disclosing ambiguous results, extent of communicating uncertainty, and confidence with which it is discussed[2]

HCP, healthcare professional.

1. Luther VP *et al. Acad Med* 2011; 86 (7): 799–800. 2. Fallowfield L *et al*. *Breast Cancer Res Treat* 2019; 177 (3): 641–649.

Messaging format

Messaging formats affect **patients' understanding** of harms and benefits and risk perceptions, and influences behavioral intentions

People tend to **overestimate** harms presented in non-numeric formats and **underestimate** those in numeric formats

Personal experiences and an ability to **visualize** outcomes can be very influential

Slide courtesy of Lesley Fallowfield.

Ask the audience

Describing frequencies

You have received a prescription for a new drug to help with indigestion and learn that the side effects include:-

Headaches

Constipation

Itchy rashes

Increased heart rate

These worry you, but your doctor explains that:

Headaches are “fairly common”
Constipation occurs “often”
Itchy rashes are “unlikely”
Increased heart rate is “very rare”

How many people out of 100 do you think get:

Headaches ....
Constipation ....
Itchy rashes ....
Increased heart rate ....

Slide courtesy of Lesley Fallowfield.

Expressing numbers

Verbal descriptors

‘Common’ or ‘rare’ are ‘elastic’ concepts that produce wildly differing estimates; overall risk grossly overestimated

Percentages confuse many

Especially if <1%

Natural frequencies work better

E.g. ‘affects fewer than 1 in 100 patients’

Combining a descriptor with a frequency is probably best

This is very rare;
it happens to fewer than
1 in every 100 patients

Helping patients to identify risks with other things they do or know about is also useful

Slide courtesy of Lesley Fallowfield.

Decision-making

Decision-making preferences

Passive	Doctor makes decision for me
Shared or collaborative	Doctor recommends treatment, taking account of my views
Active	Doctor offers information, but I make the final decision

Slide courtesy of Lesley Fallowfield.

Patient expectations about decision-making

- Ethical, legal, and social imperatives for autonomous, more collaborative decision-making, and shift toward more patient-centered care
- Patients generally want more information and more overtly collaborative participation
- Many putative benefits of improved information provision:
    - Reduced fear and anxiety
    - Less decisional regret
    - Enhanced ability to employ coping strategies
    - Better adherence to advice/management plans
    - Improved overall quality of life

Slide courtesy of Lesley Fallowfield.

What is ‘best’

Assumption that a shared approach is ‘best’ (value-laden assumption in itself)

Relationship is not usually symmetrical

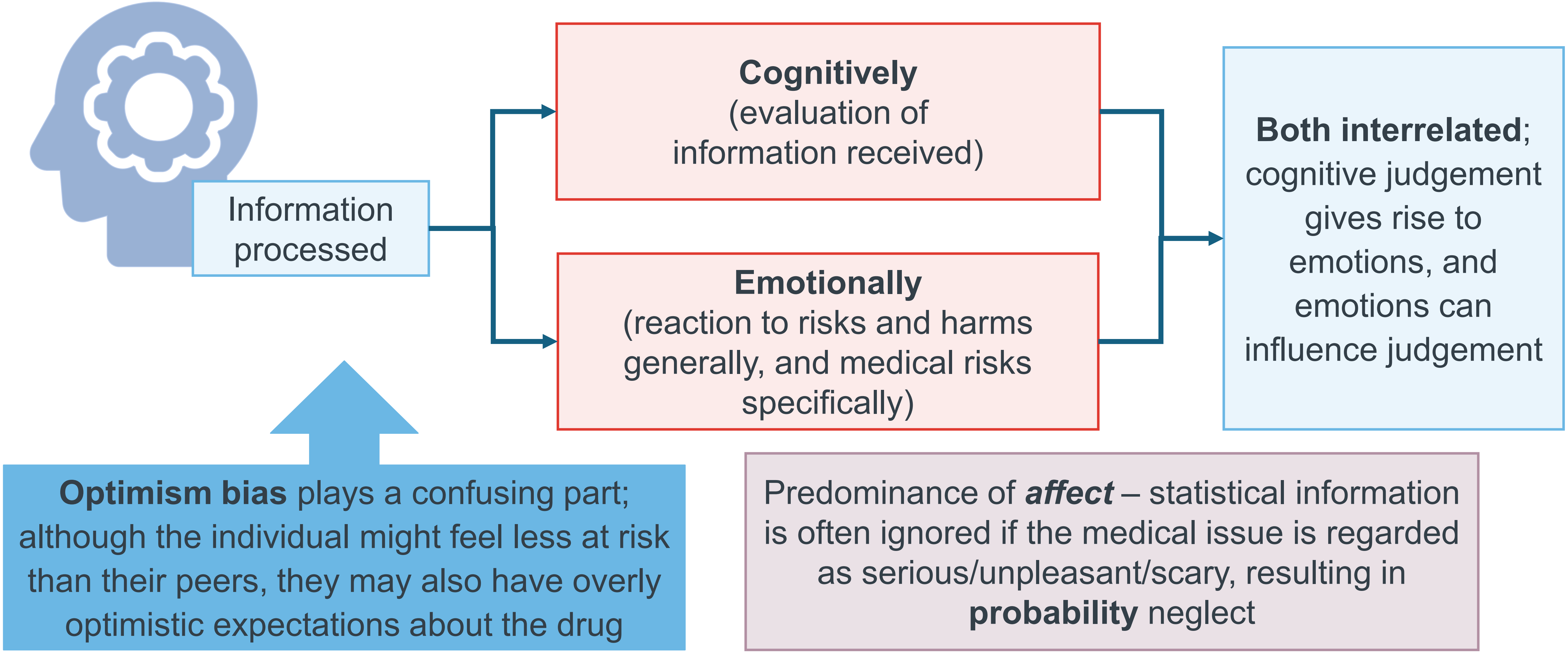
Difficult for sick, anxious patients to convey values, lifestyle, and preferences unless there is active probing, so some decisions may seem irrational

Doctor has considerable power through knowledge and does not have to experience the consequences of treatment

Not easy to ‘share’ decisions if one has a clear view of what might be in a patient’s best interests

Slide courtesy of Lesley Fallowfield.

Decision-making is rarely rational



Information processed

Cognitively
(evaluation of information received)

Emotionally
(reaction to risks and harms generally, and medical risks specifically)

Both interrelated; cognitive judgement gives rise to emotions, and emotions can influence judgement

Optimism bias plays a confusing part; although the individual might feel less at risk than their peers, they may also have overly optimistic expectations about the drug

Predominance of ***affect*** – statistical information is often ignored if the medical issue is regarded as serious/unpleasant/scary, resulting in **probability** neglect

Slide courtesy of Lesley Fallowfield.

Decision-making: ‘Acute’ and ‘chronic’ issues

Surgery, IV systemic, and radiotherapy decisions are ‘acute’; mainly irreversible	The patient has a passive role during treatment
Oral medication, diet, and exercise are fundamentally different ‘chronic’ decisions; reversible	The patient is required to actively make daily decisions

IV, intravenous.
Slide courtesy of Lesley Fallowfield.

Giving complex information and dealing with information overload

- The amount of information required for **educated, informed consent** is a problem:

Patient Information Leaflets and Informed Consent Forms (PILs and ICFs) may help, but research shows that few read them

Usefulness correlates with health literacy and numeracy, which are very low worldwide

A study of 154 PILs/ICFs showed that most were far too complex, with only 7.1% evaluated as ‘Plain English’[1]

Few complied with best practice literacy guidelines

Other research shows that the top reason for trial entry is ‘trust in the doctor’[2]

Implies that verbal communication has greater influence on patients’ decisions than written word

1. O’Sullivan L *et al*. *BMJ Open* 2020; 10 (9): e037994. 2. Jenkins V *et al*. *Br J Cancer* 2000; 82 (11): 1783–1788.

Health literacy and numeracy are low

Most health information leaflets are too complex for 43% of UK adults (61% if numeracy as well as literary skills required)[1]

1 in 5 adults feel anxious when given numerical information[2]

Often, **irrelevant information** has more influence on those who are less numerate or who may make decisions based on less complete, poorly understood information

Only 49% have the expected level of numeracy of a primary school child[3]

Only 22% of working-age adults are functionally numerate[3]

HCPs must be able to convert numbers into concepts interpretable for individuals making personal risk judgements

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HCP, healthcare professional.

1. Rowlands G *et al. Br J Gen Pract* 2015; 65 (635): e379–e386. 2. The Maths Anxiety Trust. Available at: https://mathsanxietytrust.com/index.html. Accessed December 2023. 3. National Numeracy; 2019 Autumn Report. Available at: https://www.nationalnumeracy.org.uk/sites/default/files/documents/Building_a_numerate_nation/building_a_numerate_nation_report.pdf. Accessed December 2023.

Enhancing decision-making

- The patient must have information delivered in a kindly, well-paced, non-patronising manner appropriate for the individual about:
  - All options
  - Therapeutic intent (cure, palliation, cancer control)
  - What is involved: treatment regimens, visits required, length of treatment, associated risks, harms, putative benefits
- If information is insufficient, patients are easy prey for charlatans on Dr. Google; some information is helpful or benign, whereas other information is dangerous or wrong
- In general, social media can raise patients' and relatives' treatment expectations
- Various studies in oncology over the past 20 years show a mismatch between patients' information/decision-making preferences and what actually occurs[1]

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[1] Tariman JD *et al*. *Ann Oncol* 2010; 21 (6): 1145–1151.

(Mis)information from the media/internet

Patients may access information from a variety of sources that may undermine that given by health carers

Some sites often make treatments seem fairly straightforward

Newspaper articles and the media describe the latest ‘wonder’ drugs, which might have only just finished Phase I/II trials

Typing *“which is the best treatment for CLL”* into Google in Nov 2023 produced >9 million hits. The first one was a center offering ‘cures’ without chemotherapies.

CLL, chronic lymphocytic leukemia.
Slide courtesy of Lesley Fallowfield.

How to help

Get a motivated person in your team to look up treatment on the internet

Recommend certain 'approved' sites, but check them – they do not always have the same information that you have given out!

Read the newspaper articles and consider responses as a team if patients query treatment

Make sure that even peripheral MDT members are aware of the principles of the trial

MDT, multidisciplinary team.
Slide courtesy of Lesley Fallowfield.

Talking about trials

Randomization

Handling uncertainty and anxiety

Giving complex information and dealing with information overload

Dealing with (mis)information, the media, and the internet

Explaining randomization

Slide courtesy of Lesley Fallowfield.

Randomization issues

Patients are rarely familiar with scientific methodology

Some may be quite suspicious about reasons for a no-treatment arm

Others may have clear preferences for an arm, which might not be available outside the trial setting

Slide courtesy of Lesley Fallowfield.

Ask the audience

How do you describe randomization to your patients?

Once you have entered the trial…

A. A computer will randomly allocate you to one of two possible methods of treatment.
B. A computer will perform the equivalent of tossing a coin to allocate you to one of two methods of treatment.
C. You will be randomly allocated to one of two possible methods of treatment by chance alone; that is, independent of who you are and who your doctor is.
D. A computer will perform the equivalent of drawing names out of a hat to decide which of two methods of treatment to allocate you to.
E. A computer and not a doctor will decide which of the two treatments to give you. Its decision will be random and due to chance alone, and not based upon the patient's or the doctor's decision.
F. You will be allocated to one of two treatments with equal chances of each treatment being the one you will receive.
G. One of two methods of treatment will be chosen by chance, and not by a decision made by the patient or the doctor.
H. Other

Slide courtesy of Lesley Fallowfield.

How to describe randomization

Paucity of research on the ‘best’ way to describe randomization

We surveyed 200 patients’ and 341 lay people’s preferences then compared these with the preferred practice of 200 clinicians[1]

Patients and lay people most disliked the analogy ‘tossing a coin’, although this was most used by 26% of oncologists

The preferences of 600 heterogeneous patients’ using actual descriptions of randomization from an ongoing trial informed consent form showed:[2]

- Most disliked was technical, complex language from the NCI website
- The most preferred description was from a cancer charity

NCI, National Cancer Institute.

1. Jenkins V *et al*. *Br J Cancer* 2002; 87 (8): 854–858. 2. Jenkins V *et al*. *Br J Cancer* 2005; 92 (5): 807–810.

Cancer charity description

> *"Once you have agreed to enter the trial, you will be randomized to a course of treatment. This means that a computer will randomly allocate patients to treatment groups in the trial. This is done so that each group has a similar mix of patients of different ages, sex and state of health"*

Patients liked the fact that the reasons for randomization were provided

Jenkins V *et al. Br J Cancer* 2005; 92 (5): 807–810.

How to help

1) Start with issues that are clear and permit a ‘platform of certainty’

“Having looked at all your test results and examined you, we know from all the research done that the best way to deal with this type of cancer is … (standard therapy) *and so that is what we can offer you today.”*

2) Then move on to describe the trial

“We are always trying to find ways to improve how we treat this disease, so some of the best experts have designed a research study / clinical trial to do this. Would you like to learn more about the research?”

Slide courtesy of Lesley Fallowfield.

Psycho-social implications of indolent cancer

What patients think about ‘watch and wait’ management

- HCPs understand the logic for ‘watch and wait’ (W&W) policies in chronic hematological cancers with their relapsing and remitting pathway

- In the context of life-threatening disease, it is difficult for patients to be told that their cancer is incurable but treatable, but that they will only be given treatment at signs of progression to produce remission or improve quality of life

- It is important to help patients understand potential iatrogenic harms associated with active treatment

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Anxiety and depression in patients undergoing treatment or W&W management

- A systematic review involved 18 studies measuring psychological morbidity in 2,720 patients undergoing treatment or W&W[1]

	W&W	Treatment	*P*-value
Anxiety (n=2,520)	24.5%	34%	0.195
Depression (n=2,720)	16.1%	31.3%	<0.05

- No significant difference in prevalence of anxiety between W&W and treatment[1]
  - Anxiety prevalence was higher in both groups than in a previous report for the general population (7%)[2]

- Depression prevalence was significantly higher with treatment than with W&W[1]
  - Depression prevalence was again higher in both groups than in the general population (5%)[2]

W&W, watch and wait.

1. Russell K *et al. Eur J Cancer Care (Engl)* 2022; 31 (6): e13678. 2. Steel Z *et al. Int J Epidemiol* 2014; 43 (2): 476–493.

Psychological morbidity and implications for communication and support

- Living with a chronic hematological malignancy has a negative impact on quality of life for patients undergoing W&W management or active treatment[1]
- The apparent equal levels of anxiety irrespective of management policy is likely due to the threatening and uncertain nature of a cancer diagnosis for both groups
- Higher depression in treatment groups than in W&W groups is possibly due to the perception that illness is now more severe?
- W&W is in contradiction to early intervention cancer policies for many countries and challenges lay expectations
- Less frequent contact may exacerbate patients’ feelings of vulnerability
- Undoubtedly, more research is needed on interventions to help patients

W&W, watch and wait.

[1] Youron P *et al*. *Eur J Haematol* 2020; 105 (6): 755–762.

Need for better educational programs for HCPs

HCP, healthcare professional.

Training programs

There are plenty of communication skills programs, but evidence for transfer of skills to the clinic is lacking for many

More work is needed to ensure that conversations about serious illness are done well and occur earlier

They must include patient-centered domains

And take some account of the emotional toll on professional caregivers

Slide courtesy of Lesley Fallowfield.

Personal and professional boundaries

- Effective communication is a core clinical skill with beneficial impact on HCP–patient relationships
- Training should help doctors to communicate in a clear, honest, and empathic manner
- Training must include something on navigating boundaries between personal and professional involvement
- Encouraging doctors to get closer to the emotional needs of patients and carers puts doctors at psychological risk

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Displaying empathy

- Empathy and emotion are different
- Empathy requires understanding of **a patient's** emotions or state of mind
- Emotions are focused entirely on **one's own feelings**
- Consequently, it is possible to:
  - Be empathic without showing emotion
  - Show emotion but not be empathic

Slide courtesy of Lesley Fallowfield.

Top tips and summary on communication about risk and uncertainty in hematological cancers

How to help

Ethical requirement that information is standardized, but individuals' needs differ depending on literacy / personality type, etc.

Remember to signpost, group facts, check understanding, and summarize

Acknowledge both patient anxiety and the volume of information; encourage patients to ask questions

Ensure that all members of the MDT are on message

MDT, multidisciplinary team.
Slide courtesy of Lesley Fallowfield.

Rehearse difficult conversations

I wish you could just tell me what is best to do?
"I'm sure this is difficult, but if we knew exactly what might be best, we wouldn't hesitate to tell you. This is why we'd like you to consider entering the … trial, so that we'll be better able to advise patients in the future. Tell me what concerns you most and we'll try to help you make a decision that feels right for you."

I just don't like the idea of 'doing nothing'…
"Rest assured we'll not be 'doing nothing'. Active monitoring means careful assessment at each appointment and if it becomes clear that further treatment is needed, we will offer you that."

What if I don't do anything now and the cancer progresses?
"This is understandable, but if there are any signs of progression that would be helped by treatment, then the active monitoring will pick it up. Furthermore, if there is no progression, then you will have been spared unnecessary treatment."

Slide courtesy of Lesley Fallowfield.

Optimal communication

- Starts with a platform of certainty about the issues that are clear before moving on to uncertainty
- Grounded, credible, reality-based possibilities of likely outcomes with different treatment(s) should be offered; discuss the risks, not just the benefits
- HCPs must know the data and question their own motives for any recommendations
- Remember the poor health literacy and numeracy skills of most patients
- How familiar you become to medical concepts and terminology which are uninterpretable by patients

HCP, healthcare professional.
Slide courtesy of Lesley Fallowfield.

Communication considerations with patients

Many words and phrases are meaningless, counter-intuitive, or ambiguous; numeracy and literacy levels are low

Health literacy affects retention of results and capacity for processing, understanding, and decision-making

Lay populations, especially if anxious with low tolerance of ambiguity, believe, in the context of life-threatening disease, that more treatment is better than less

HCPs’ own communication about risk, harms, and benefits is subject to unconscious biases and misunderstandings

Need improved strategies when explaining things (otherwise, patients are probably not making informed choices about options)

HCP, healthcare professional.

Slide courtesy of Lesley Fallowfield.

Rob Buckman (1992)

“Almost invariably, the act of communication is an important part of the therapy: ***occasionally it is the only constituent****.*

It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses.”

Buckman R. Communication in palliative care: A practical guide. In: Oxford Textbook of Palliative Medicine. 2nd ed. Oxford University Press; 1998.

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Colleagues at:

SHORE-C

Sussex Health Outcomes Research & Education in Cancer

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