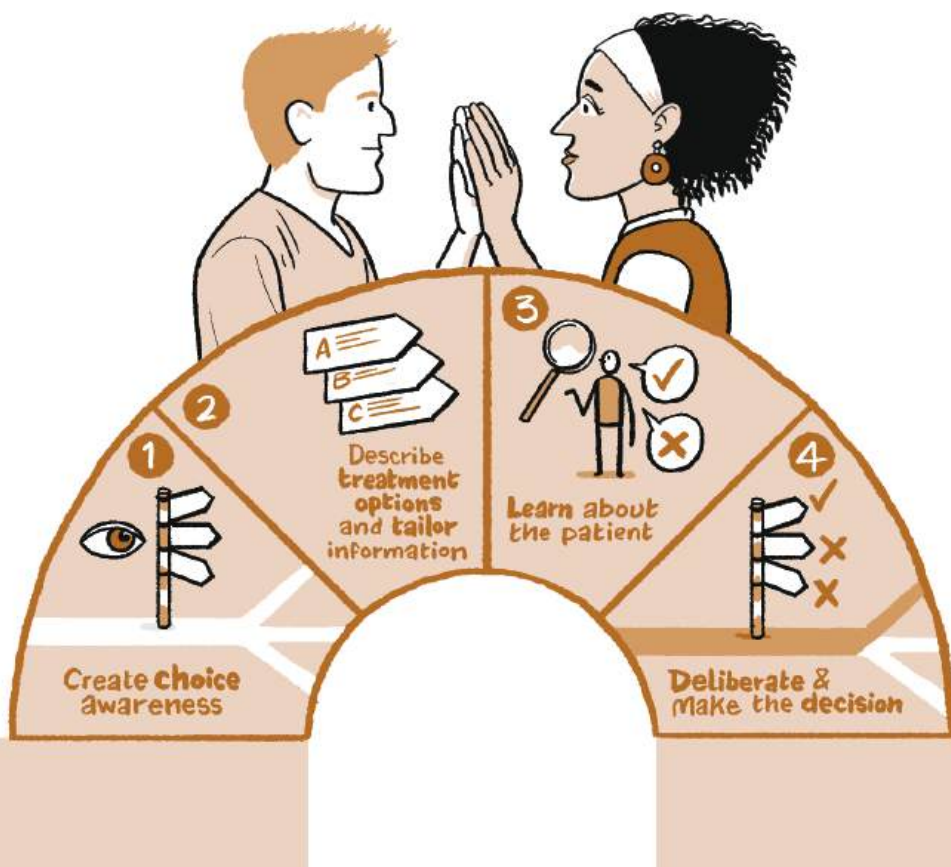


Shared Decision-Making



Making conversations easier

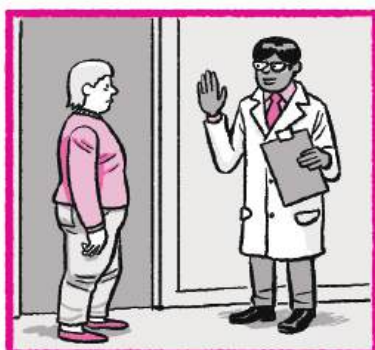
“

Shared decision-making is both complex and simple. It asks clinicians to set aside ready-made answers and stay curious, and it asks patients to dare to be fully seen. In that meeting, with humility, courage, and compassion, clinician and patient shape care that honours this person's life and priorities.

inspired by Pieterse AH et al., 2019, 2022, 2023

- Pieterse AH, Gulbrandsen P, Ofstad EH, Menichetti J. What does shared decision making ask from doctors? Uncovering suppressed qualities that could improve person-centered care. *Patient Educ Couns* 2023;114:107801; <https://doi.org/10.1016/j.pec.2023.107801>
- Pieterse AH, Stiggelbout AM, Montori V. Shared decision making and the importance of time. *JAMA* 2019;322:25-26; doi:10.1001/jama.2019.3785
- Stiggelbout AM, Pieterse AH, De Haes JCJM. Shared Decision Making: concepts, evidence, and practice. *Patient Educ Couns* 2015;98:1172-1179; <http://dx.doi.org/10.1016/j.pec.2015.06.022>

Introduction



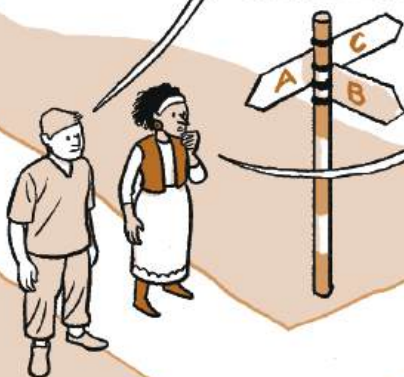
So what is
shared decision
making?

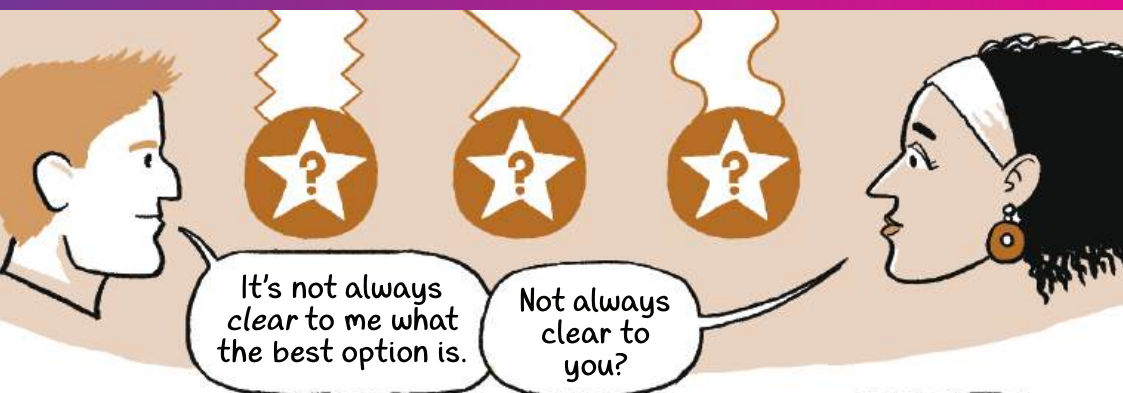
How is it different from
the *many conversations*
we have about your care?

Shared decision making
is recommended when
there is *more than one*
reasonable option.

More than
one option...?

Yes.
Sometimes there
is more than one
reasonable option, and
it isn't obvious which
one is *best* for me.

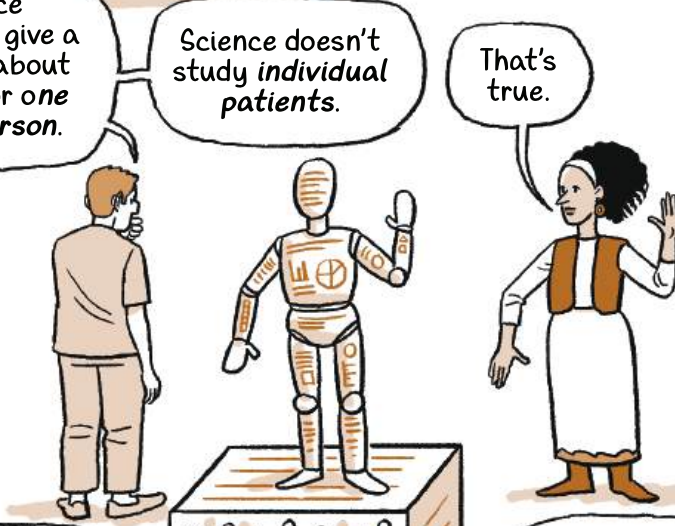






That takes judgement.

Tell me more about that.



The evidence doesn't always give a clear answer about what's best for one particular person.

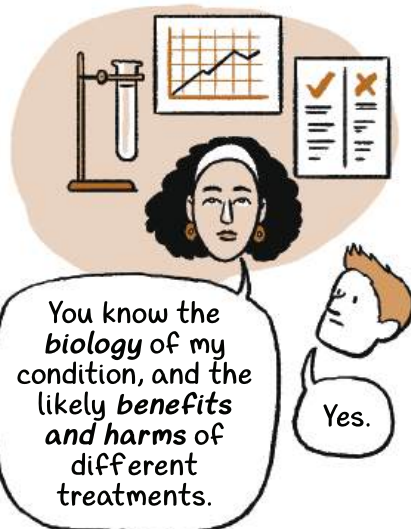
Science doesn't study individual patients.

That's true.

It tells us what medicine knows – and doesn't know – about diseases and treatments in groups of people.

So you then have to take this evidence and adapt it to support me in deciding how to proceed.

Exactly.



If you don't invite me in, you risk only *superficially* involving me in decisions about my care.

Tell me more.



You must go further – to find ways the *evidence* can support me in deciding how to proceed...



...and to learn what is important to me:



my lived experience...

...my values...

...my goals...

...and my concerns.



How can I
do that?

Start a
conversation
with me.



Create space where we
can *explore the evidence*
together and talk about
my preferences.



It looks like
there might be
something on
your mind.

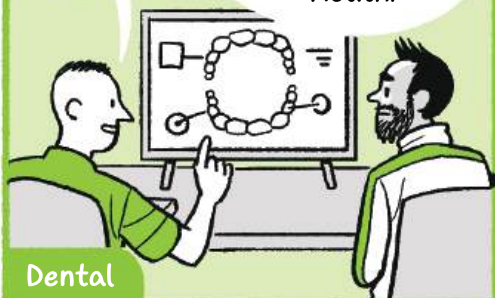
What's
been going
on for
you?



Renal

We've just
reviewed
your
X-rays.

They give
us a good look at
your four wisdom
teeth, at the
back of your
mouth.



Dental

How have your
back teeth been
feeling lately?



Show me that you *care* about the effect of my condition on me, and about how possible treatments might affect *me*, *my family*, and *my activities*.



I hear that you're worried about your joints and also about the treatments we could use.

Let's talk about that.



Rheumatology

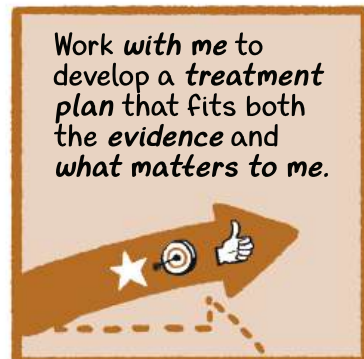
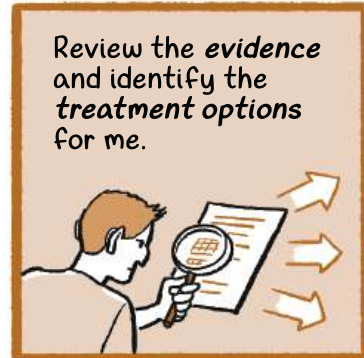
I understand you've come in today, Niamh, because you're worried about your baby's movements.

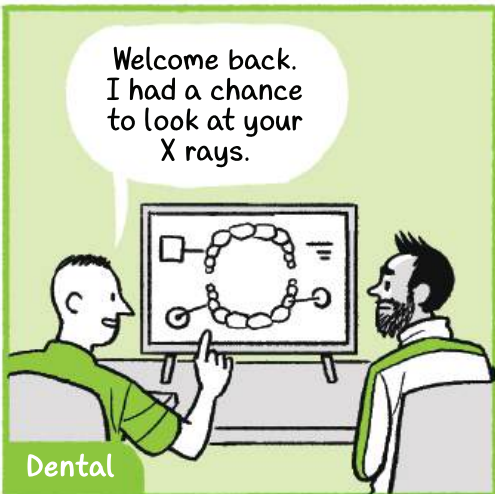
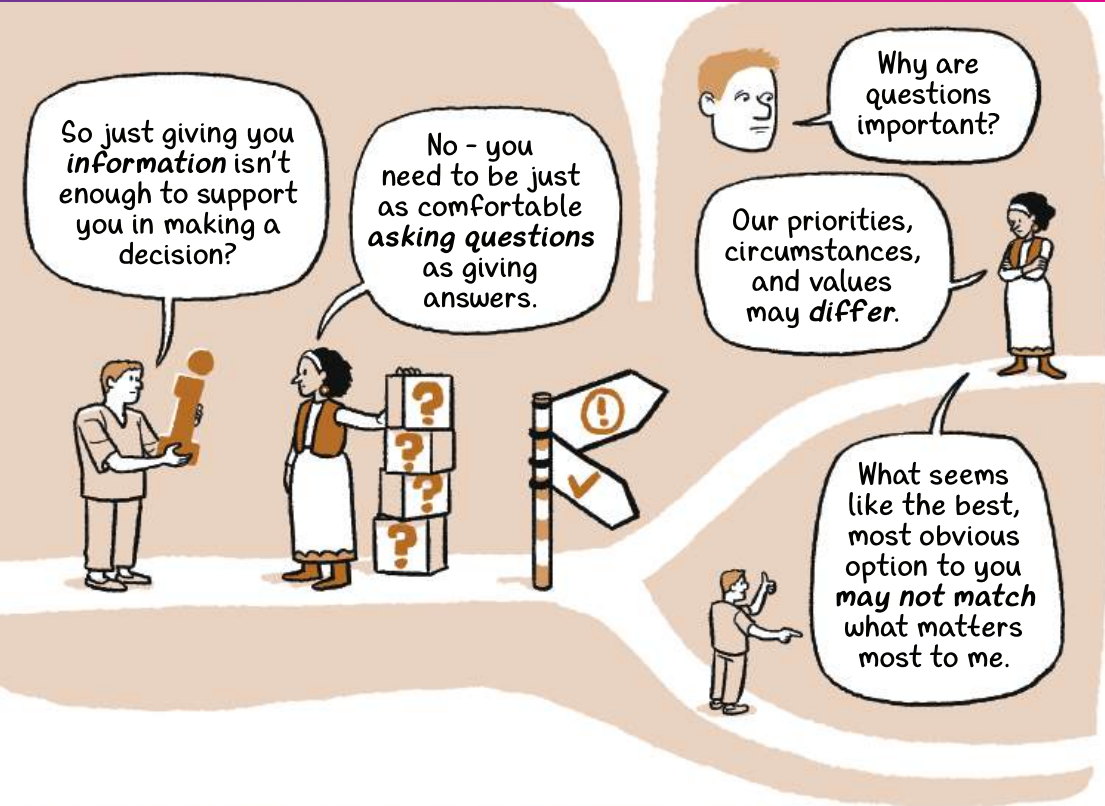


Maternity

Tell me more about that.







Sometimes you make **assumptions** about my preferences and don't check them with me.

I see...

So in this conversation, we need to **notice any differences** in how we're thinking, and work through them **together**.

Yes.

I'm going to have to **change** how I see my role.

Change?

Yes. I think in the past I may have seen my role as the **sole decision maker**.

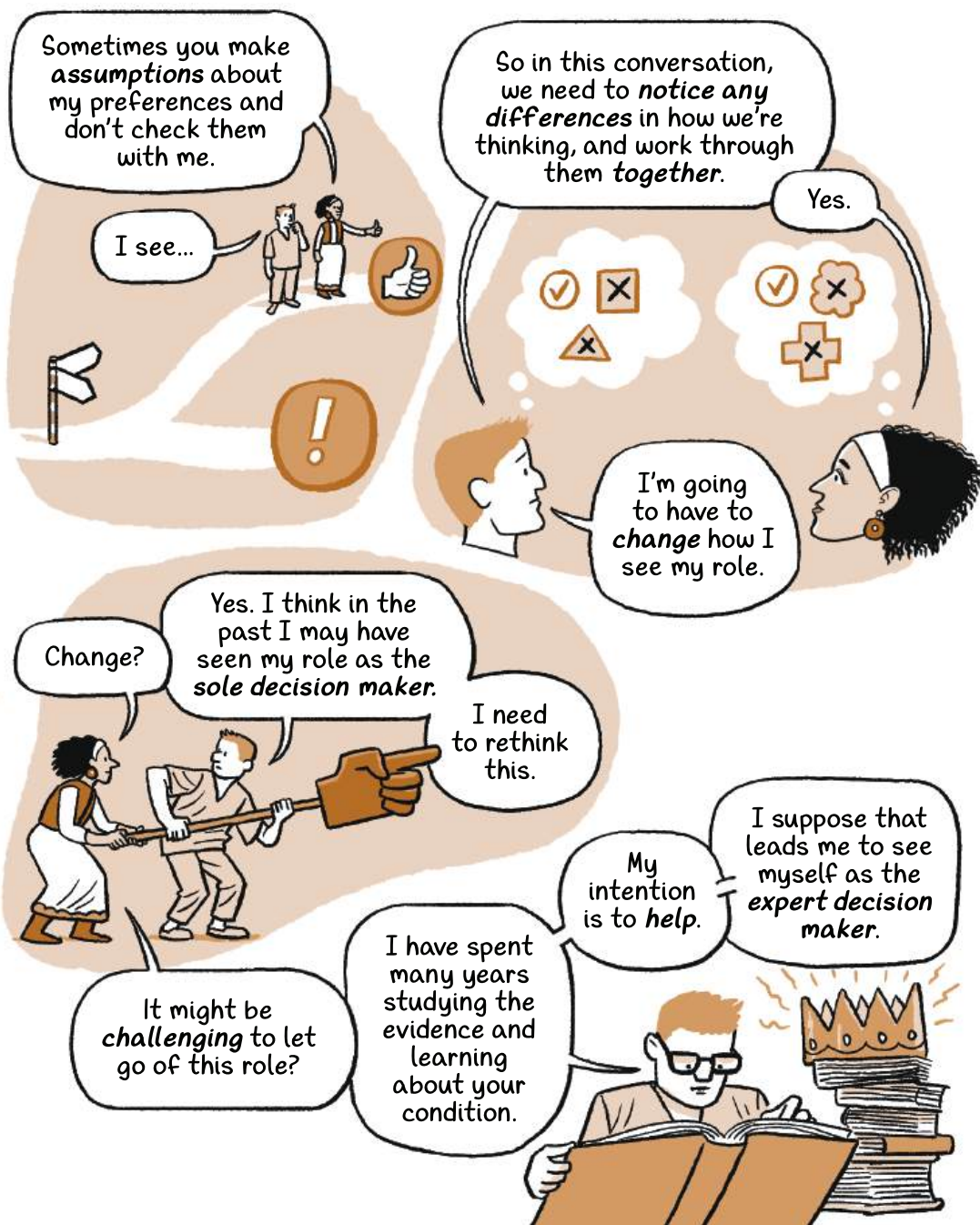
I need to rethink this.

It might be **challenging** to let go of this role?

I have spent many years studying the evidence and learning about your condition.

My intention is to **help**.

I suppose that leads me to see myself as the **expert decision maker**.



I prefer a more collaborative approach.

You are the expert in your values, goals and preferences.

There are also some things *you* could do to help.

Tell me.

During the conversation you could...

Ask me questions when I'm unclear.



Ask how treatment might affect your life and situation.



Talk about your thoughts and feelings.



Consider the options, and say what is important to you.



Outside the conversation, you could...

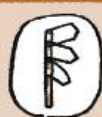
Read any information I give you.



Think about the options.



Discuss the decision with your family or others important to you.



Yes. I will need time to do that.



Time

Time is often limited in healthcare.

You can still *create space* for shared decision making, *even* when there is time pressure.

How?

You could offer to see me again *later the same day*.

Or you could start the decision making conversation *earlier*.

Ok.

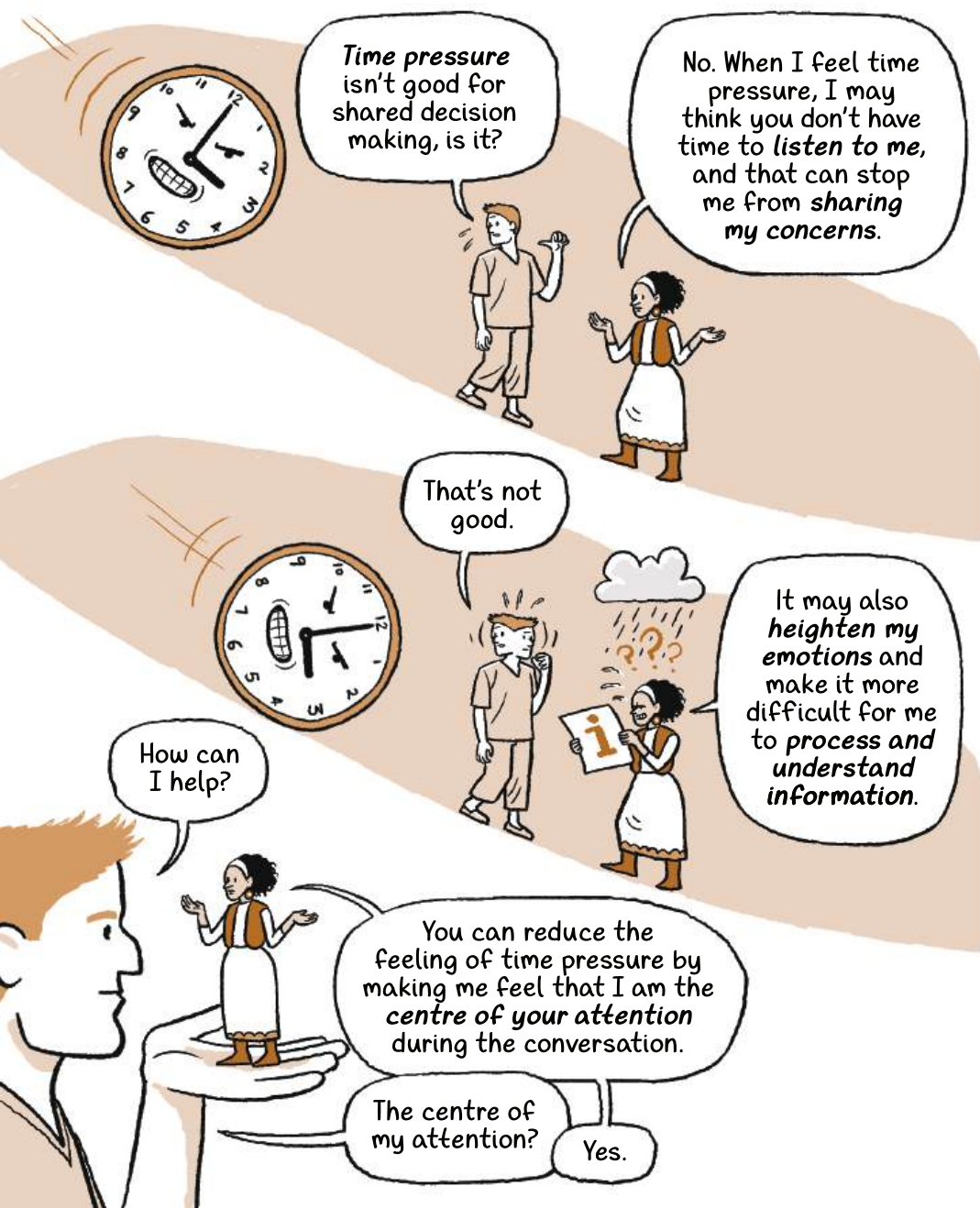
What do you mean?

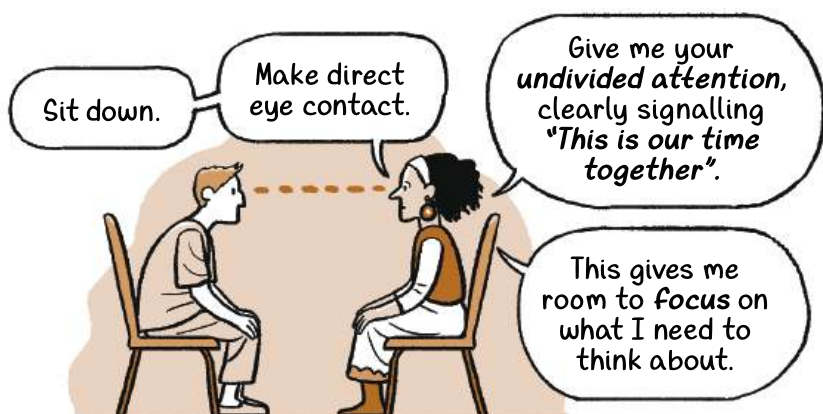
Some decisions can be anticipated *months ahead*.

Like decisions about childbirth, dialysis options, or screening – things we can often see *coming in advance*.

Yes.







Michael, I've read your notes in detail, but so that I know where to start and what to cover, tell me in your own words what's happened so far?



Silence makes me uncomfortable.

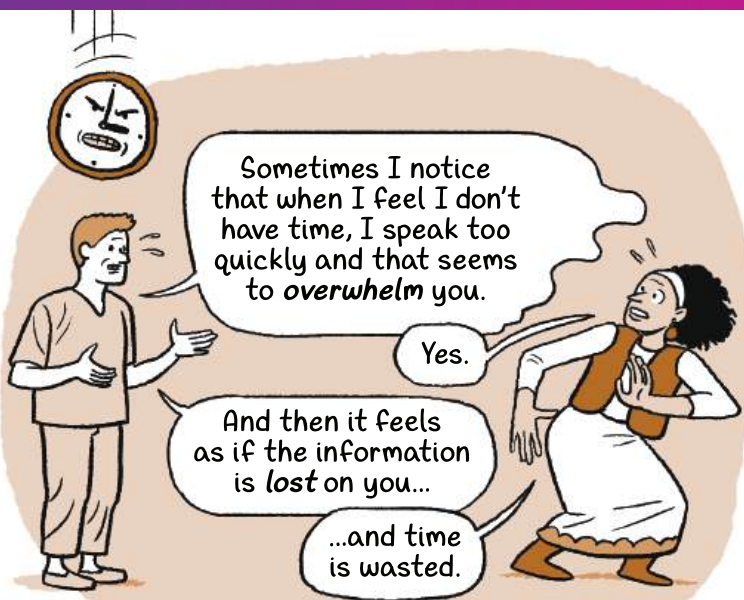
Try to embrace it.

A silent pause gives me time to think...

...to share more information...

...or to ask questions that might be important for us to make the decision together.





Allowing a silent pause lets me *process* what you've said and *decide* what I need to ask or tell you next.



Why is *shared decision making* so important to you?

When you listen to me and explore my needs, it helps to *improve* our *relationship*.

It creates an environment where *I feel safe* to express my worries and say what is important to me.



RELATIONSHIP



And what else?

When we make the decision *together*, it helps me follow through with the decision and the treatment plan.

Why?

Because if you hear my worries and concerns, you can *align the treatment options* with my needs and circumstances.

Then we come up with a plan I am comfortable with.

It sounds like both the look and the function are important to you.

We can certainly address both the crowding and your bite.

I still have all the worry of whether the cancer is really gone or not, and what I'll do if it comes back.

Dental

Surgery



Would it cost more for me to have the dialysis at home?



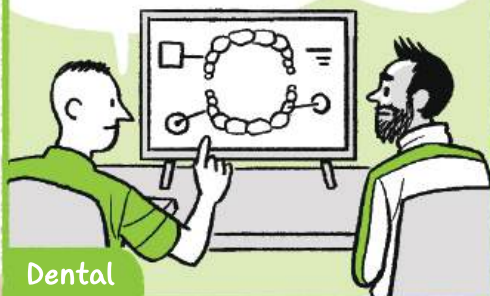
Renal

I mean the machine uses electricity, home dialysis will affect my electricity bill.



We've just finished the examination, and I've found a cavity on that lower right molar we were looking at.

It needs a filling.



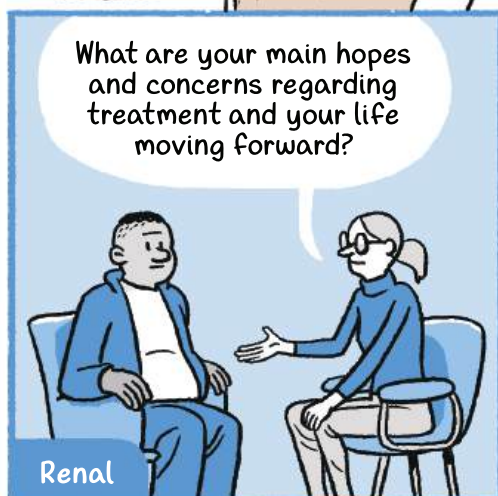
Dental

The usual option is a tooth coloured composite filling, and I'd like to talk you through what this involves and what would work best for you.



There is so much to consider...





Emotions

You mentioned that your *emotions* can affect our conversation.



Emotions can be both *helpful* and *unhelpful* in making decisions.



How so?

I am likely to experience *distress* due to my diagnosis, and that can make it difficult for me to be involved.



It might not be easy for you to *express yourself*...

If I'm just completely *emotionally paralysed*, I might think '*whatever, it just has to be done*'.



And then you won't get involved?

That's right.



Emotions may also limit my understanding of information.



I might focus on just *one piece of information* and miss other important parts.



That would hinder your ability to make a decision?

Yes.



So to help you manage your emotions...



I need to create a **safe space** for you to express how you feel.



I can show support by being **empathic**...



...helping to put things in **perspective**...



...and maybe giving you some time alone with a **loved one or companion**.



When we were talking on the phone about this meeting, you mentioned that you were nervous.

How are you feeling today?

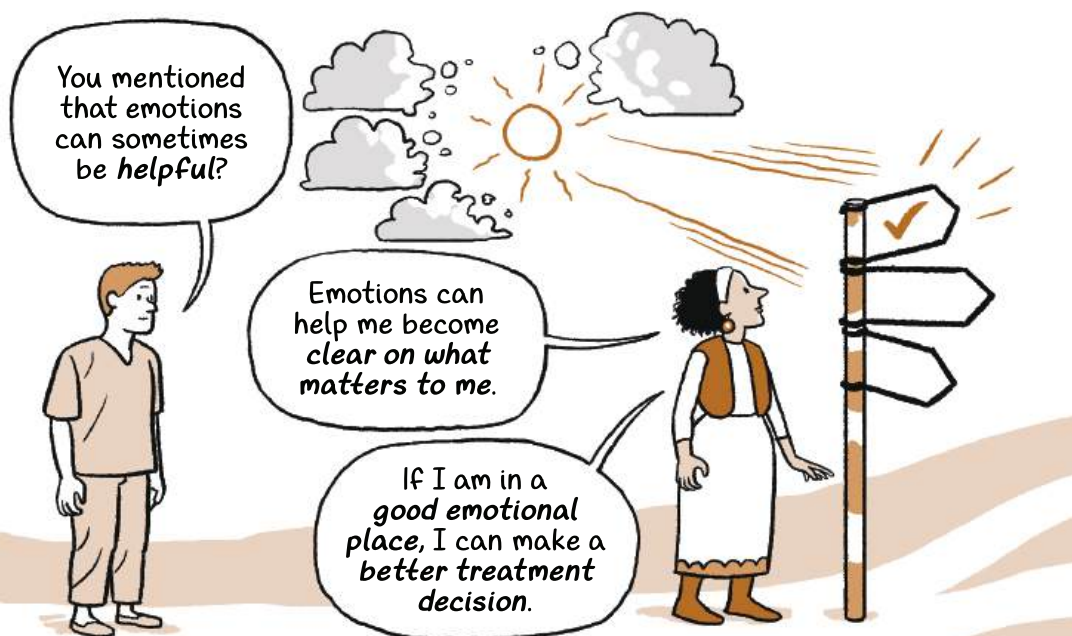
Maternity

And if none of that helps, acknowledge that this is *not a good time* for me to receive information or make a decision.

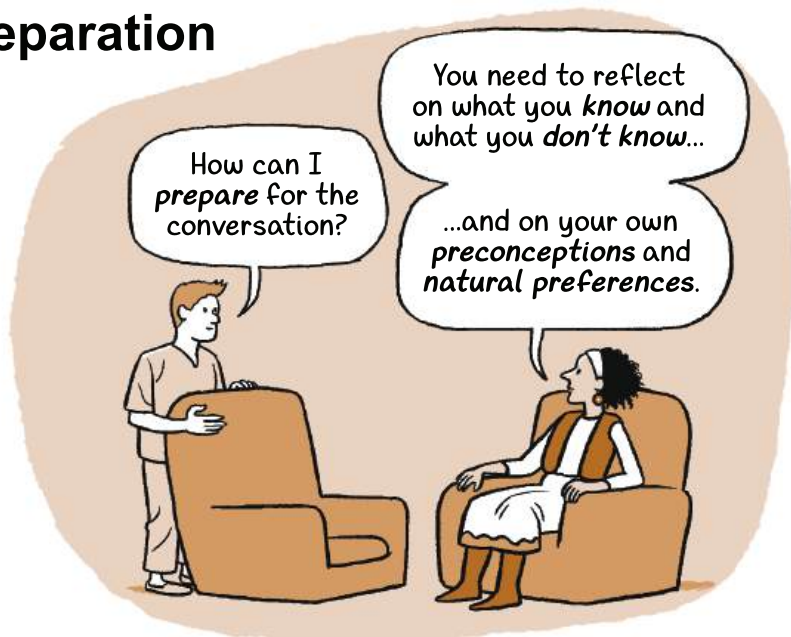
Then, if possible, *postpone the decision* for another time.

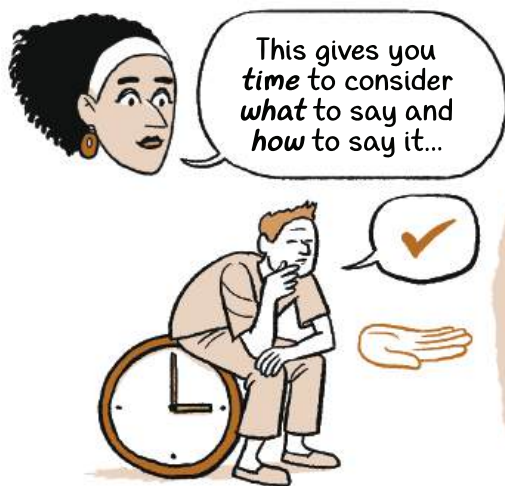
Let's meet again at your next visit to continue this discussion about your options for delivery.

What would you need in the meantime to help you arrive at a preference?

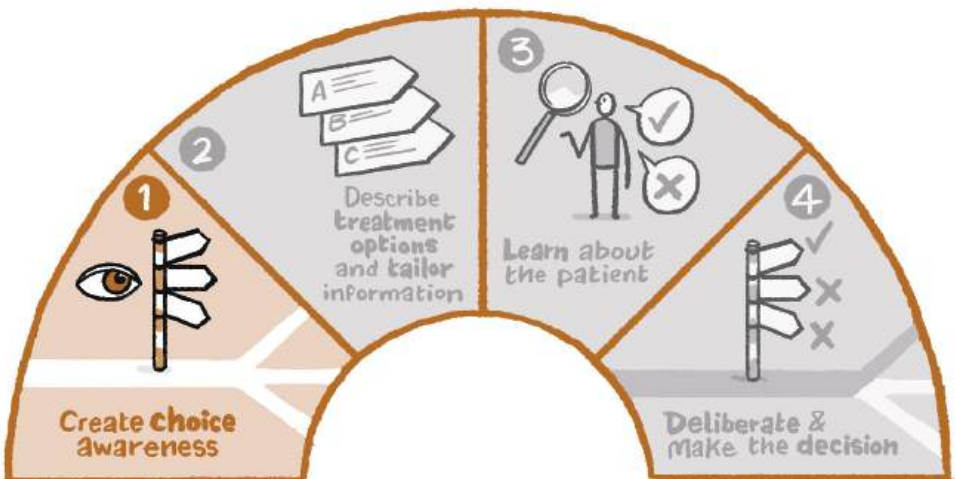


Preparation

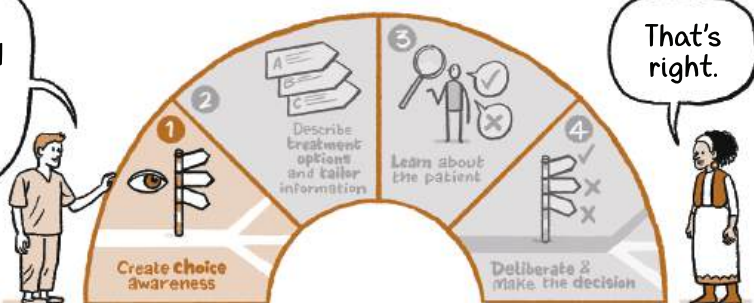




Create choice awareness



You mentioned four stages, and the first is to **create choice awareness**.



Tell me more about that.

To create choice awareness, you need to **clearly acknowledge** that there is **more than one option** and that there is some **uncertainty** about the best next step.

So I should **share** what I'm thinking and **involve you** in the decision making process.



There are some contraceptive options available before your discharge if that would help.

Have you thought about this?



Maternity

We have two main surgical options, and both have the same outcomes for your type and stage of cancer.



Surgery

Now that we have identified the problem, we can move on to think about what we do next.



Renal

I think there are two options that we could discuss.



And acknowledge that what each of us contributes is *equally important* to the final decision.



There are several options to manage your pain during labour and the best one depends on your preferences and delivery plan.

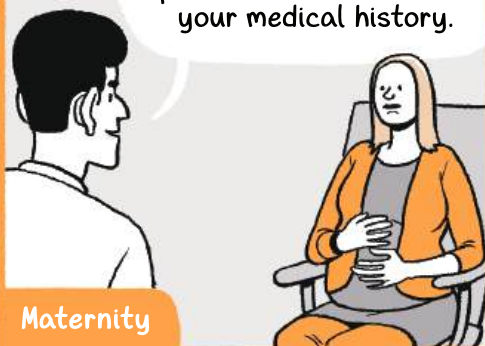


Maternity

The best option depends not only on the *medical evidence*, but also on *your personal values* and how you want to *live your life*.



Both delivery options are possible, and the safest choice depends on your preferences as well as your medical history.



Won't you *lose* trust and confidence in me if I say I'm *uncertain*?

I'm supposed to be an expert in this area...

You *are* the medical expert and I think it helps me to trust you more..



It shows me that you have the *humility* to acknowledge uncertainty...

...the *flexibility* to allow other possibilities to remain open...

...and the *courage* to jump into the unknown... *together*.



We have a few different options here...

Some of the treatments we use are tablets, some are pen injectors, and some you come to the ward for as a drip.

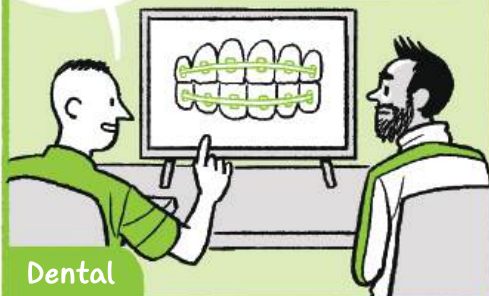


They are all good, but we need to figure out what will work best for you.

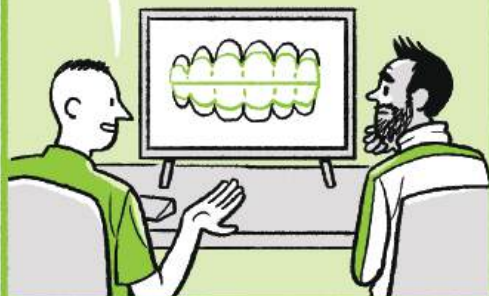


I think there are two main options we should discuss.

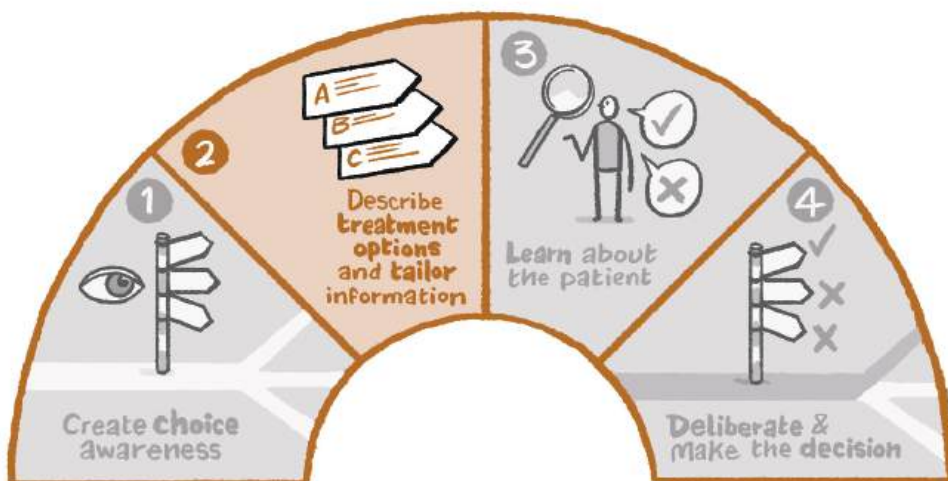
The first is fixed braces, which can be metal or tooth-coloured ceramic.

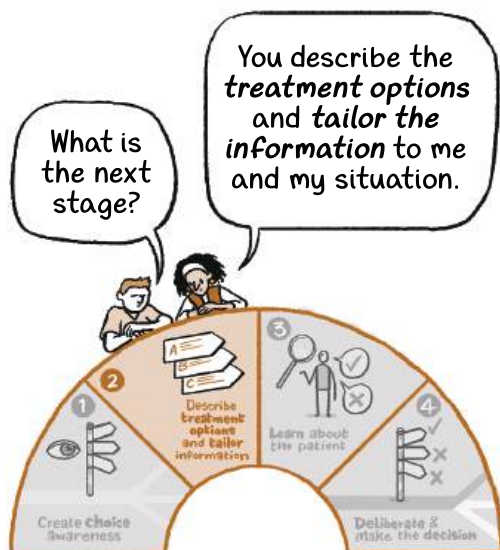


The second is clear aligners, like the Invisalign you mentioned earlier.



Describe treatment options and tailor information to individual patients

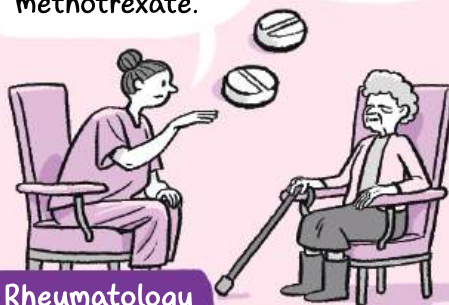




❌ 1

The most common first choice is a tablet called methotrexate.

You need to have regular blood tests while on it.



Rheumatology

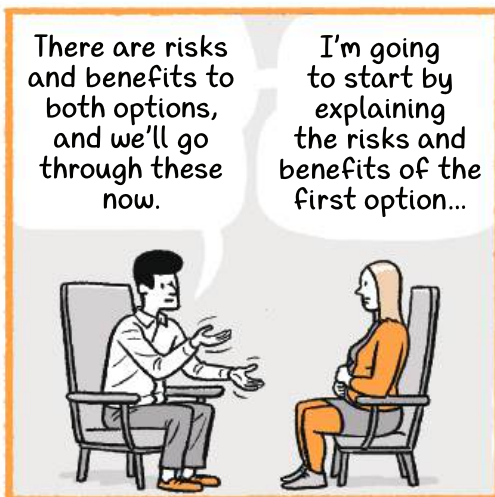
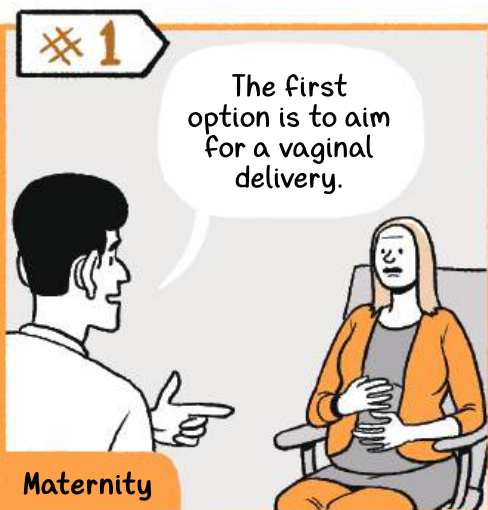
❌ 2

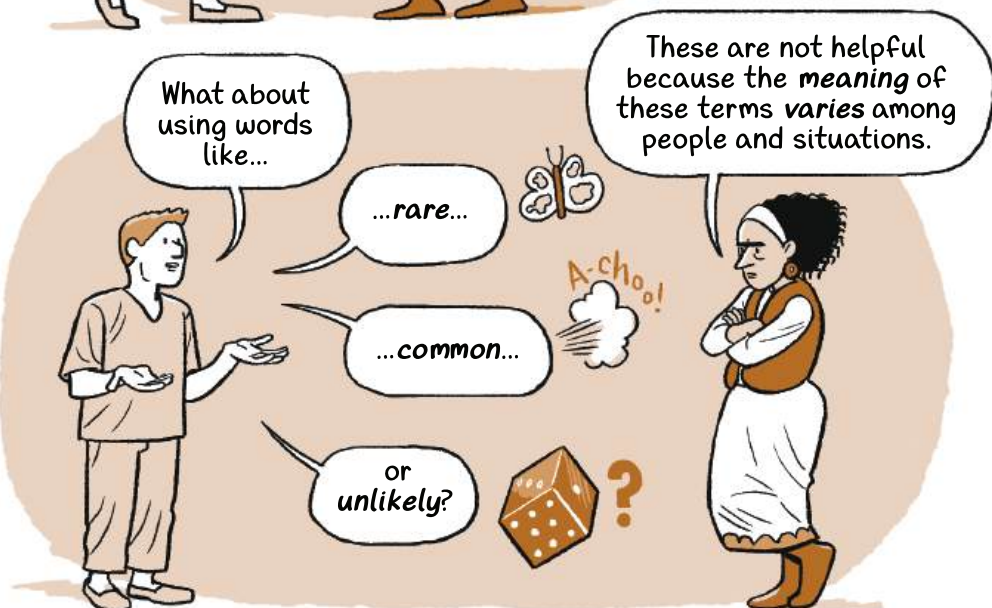
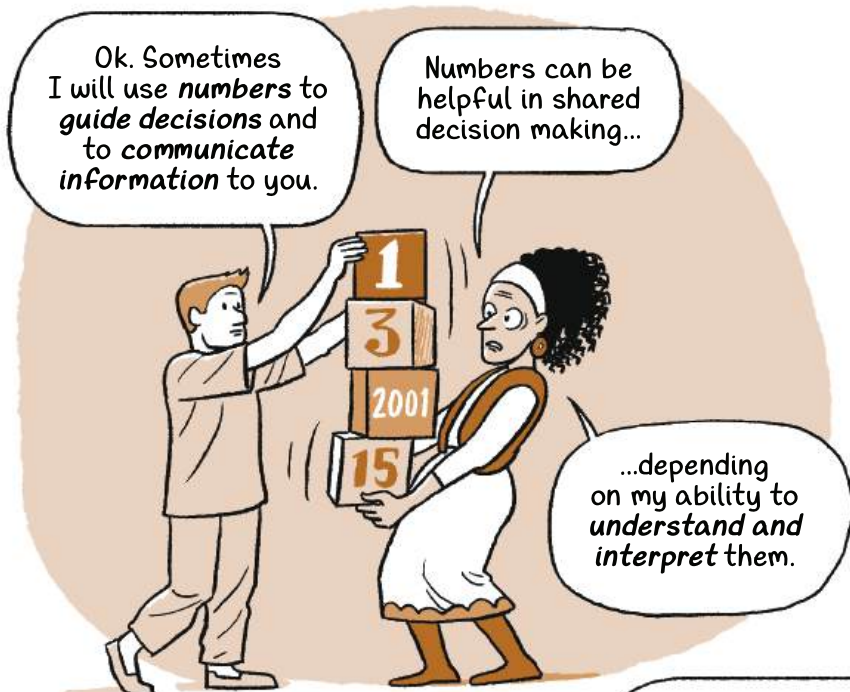
After methotrexate, we have a number of injectable drugs called "biologics."

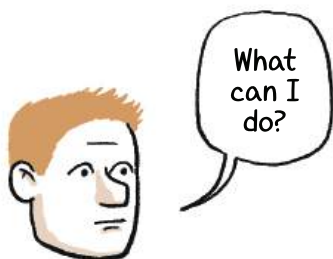


These are newer, and we can teach you about them as an alternative if methotrexate doesn't work.









First, use numbers (even approximate ones) to describe *risk probabilities*, for example:

- ✓ 45% or 70%
- ✓ 5 in every 1000
- ✓ 10% to 15%



Second, use *consistent denominators* when discussing numerical data, instead of switching to *1 in X* formats, for example:

- ✓ 10% of women
- ✓ About 7 in 1000 people



Third, present differences in probability using *absolute differences* instead of *relative reductions or increases*, for example:

- ✓ Reduces the 10-year risk from 8% to 6%



Fourth, when you use visual displays of probability, use *part to whole visualisations* such as icon arrays or stacked bars.

For Example: **8% risk** - If 8 out of 100 people are expected to have an outcome, it can be shown like this:



Fifth, provide *context* for numbers that may be unfamiliar to me, such as biomarker levels. For example:

Your HbA1c is 9.2%.
For you, our target is below 7%, and even a 0.6% change would be significant.



Ok, so I should present information using **numbers** rather than vague terms like *rare* or *common*...

...use **consistent denominators**;

✓ 10% of women

✓ About 7 in 1000 people

✓ 1 300 76 ✗

Rare
Common
Unlikely

...focus on **absolute** rather than **relative** risks...

Your HbA1c is **9.2%**. For you, our target is below 7%, and even a **0.6%** change is significant.



...and **provide context** for unfamiliar types of data.

Reduces the 10-year risk from 8% to 6%

That's it!



What else?

It's important to see how the way a message is formulated can **shape my perception**.

Tell me more about that.

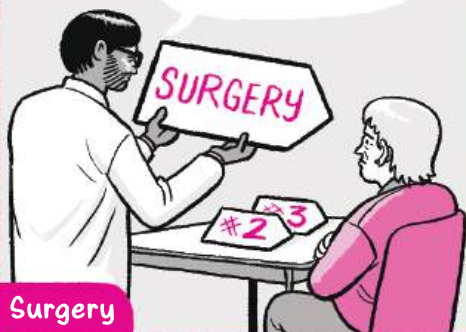
Be aware that how you present and frame information may steer me towards particular options in different ways.

Steering you?





Surgery is probably the best option for you.



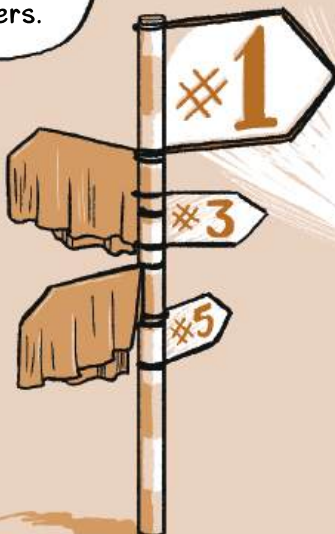
Surgery



It would deal with the problem more directly than the others, and I think it's the option we should focus on.



You may present only a *subset* of available options, or provide *more arguments* for some options than for others.

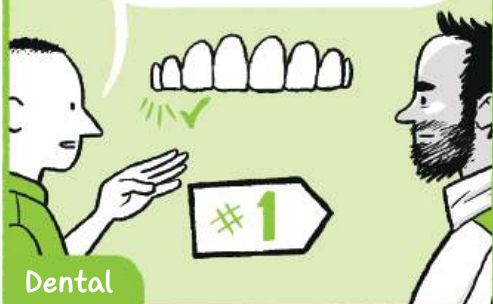


That would require me to be aware of those *framing tendencies* and to be *honest with myself* about them.





The usual option we offer for this is a tooth coloured composite filling. It blends in with the tooth and works well in most cases.



Dental



In some situations, there may be other restorative options to consider, and we can talk about what would work best for you.



Yes, and steering may also be more subtle...

...for example, when you use language that *consciously or unconsciously* drives me toward the option you think is in my best interest.





Option A has side effects that are difficult. How do you feel about that?



Renal

So when I do that, I am *implicitly steering you* in the direction that I think we should go?

That's not good.



No. It is also important to be aware of the role your own *biases* might play in influencing my choices.

So self-regulation?

Managing my emotions and behaviour...

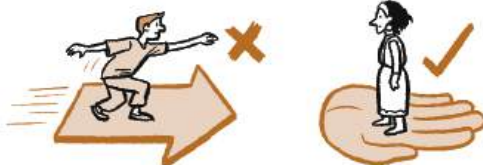
What biases should I be aware of?



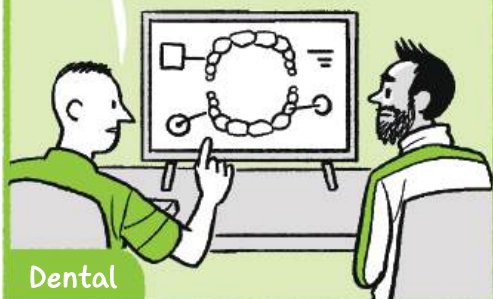
For example, the *availability bias*, which can lead you to overestimate how likely an outcome is (good or bad), because similar examples come to mind easily...



...or the *action bias*, which can result in you recommending an intervention when watchful waiting or supportive care might be better.



Based on your X-rays, your wisdom teeth are growing in at an angle and only partly through the gum.



We have two main approaches to consider:

Surgical
removal



Active
Monitoring



Both can be reasonable in your situation.

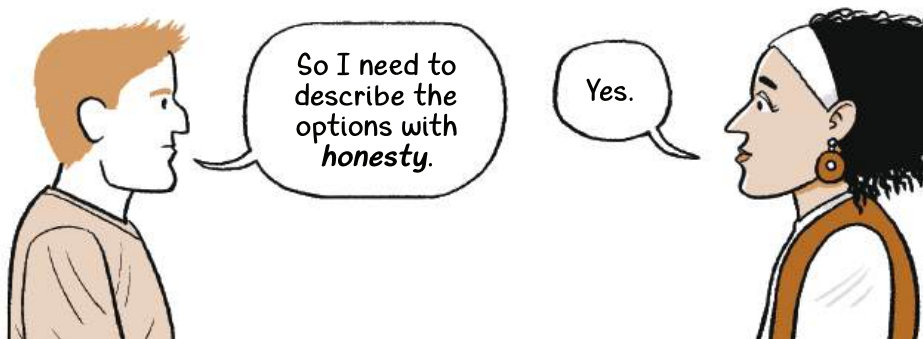


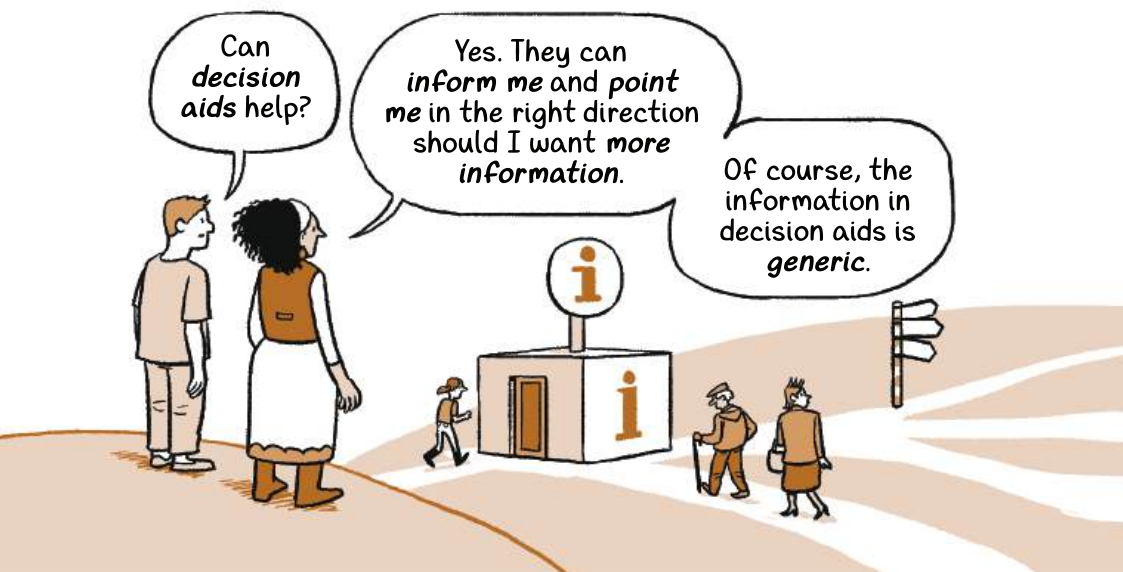
What are your initial thoughts or main concerns?

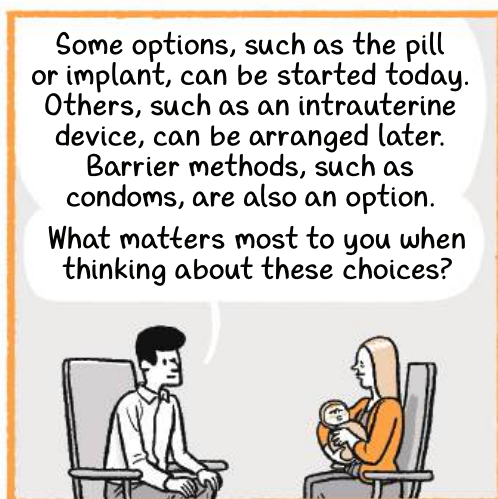
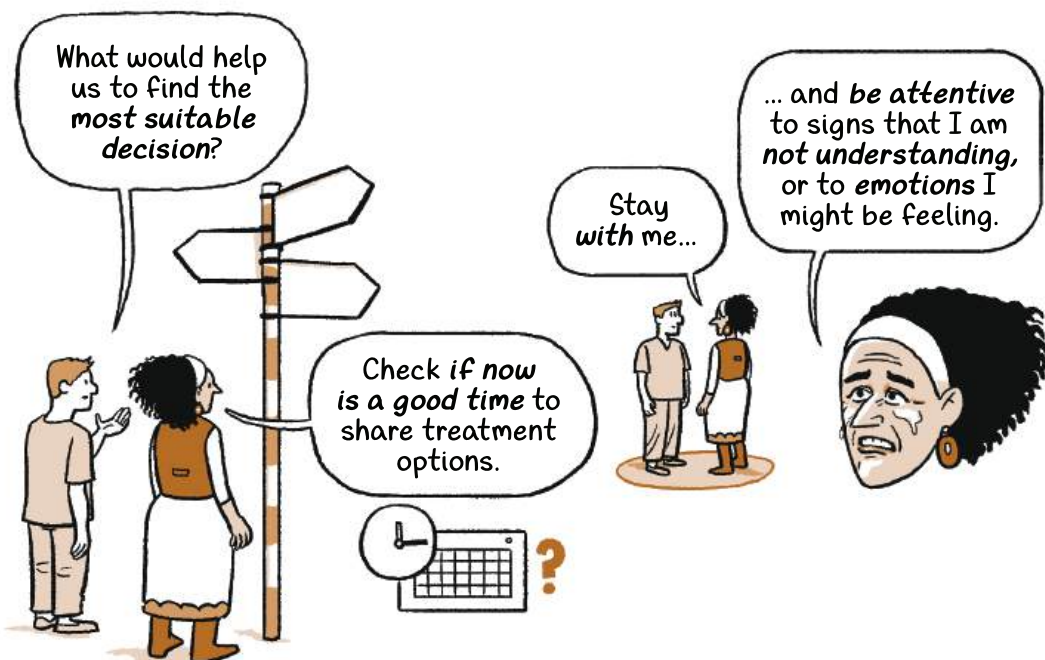


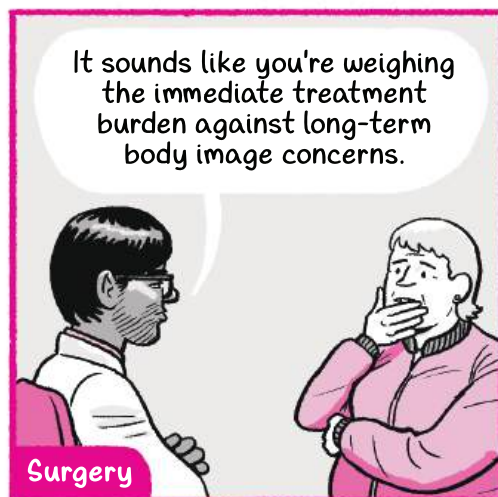
So I need to describe the options with *honesty*.

Yes.









Yes. And talk with me about what I think I can *realistically manage*, and my ability to *stick* with the decision.



How do you feel about having regular blood tests - they can be with your GP or practice nurse?



Rheumatology

What else?

It can be useful to discuss the *experience* of the healthcare team associated with each option, and any *uncertainties* around the decision.

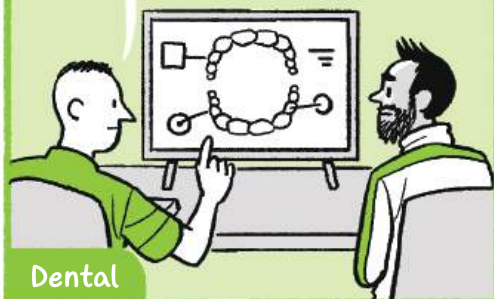


Based on what you've told us, removing the lump followed by radiation may be worth considering if keeping your breast shape is important to you.



Surgery

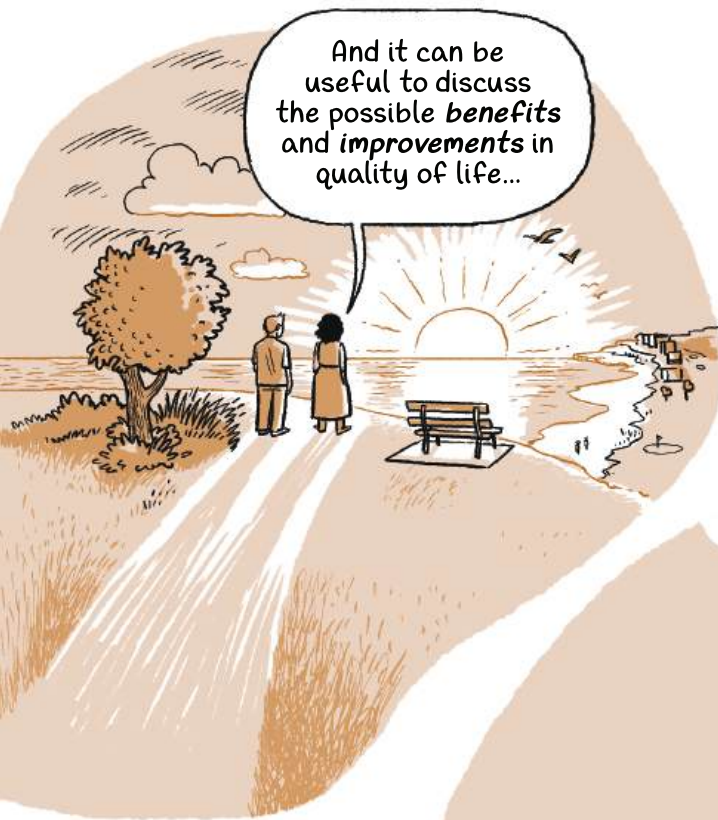
If we leave this untreated, the decay is likely to spread and could eventually reach the nerve, which can be very painful.



At that stage, a simple filling might not be enough to save the tooth.



And it can be useful to discuss the possible *benefits* and *improvements* in quality of life...



...as well as the *risks*, *side effects*, and any possible *decreases* in quality of life associated with each option.



The benefits of home dialysis include more flexibility with your schedule, less travel time, and potentially fewer side effects between treatments.



Renal

Peritoneal dialysis (through the tummy) is done daily or nightly, usually while you sleep, and allows for more flexibility with your diet.



Risks include infection and daily treatment burden.

You asked earlier about electricity costs. Let's discuss possible extra costs and supports.



You need to identify and evaluate the *relevant evidence*, integrate it into *practice*, and translate it to *my situation and condition*.



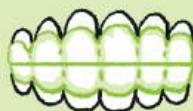
The benefit of fixed braces is that they are very effective for complex movements, including bite correction, and provide a high level of control.

These can be metal or tooth-coloured ceramic braces.



Dental

Clear aligners are less noticeable and can be removed, which often makes eating and cleaning easier.



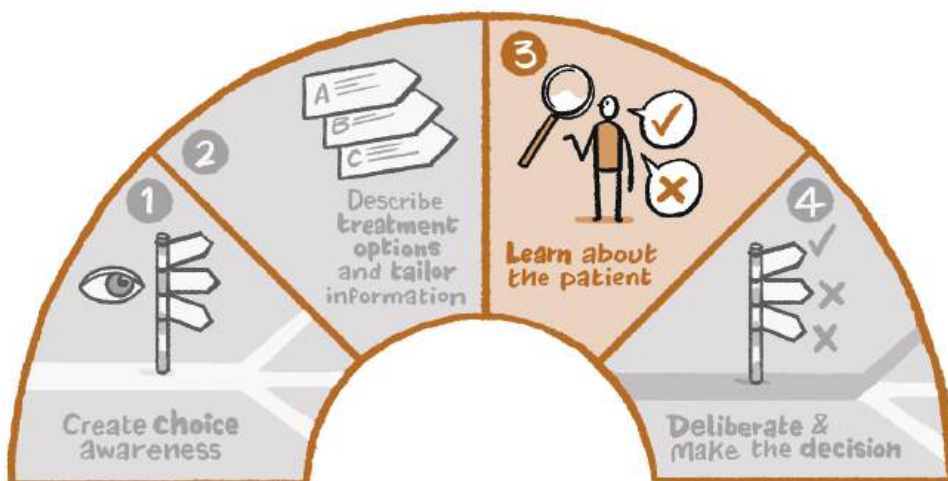
It sounds like that is important to you.

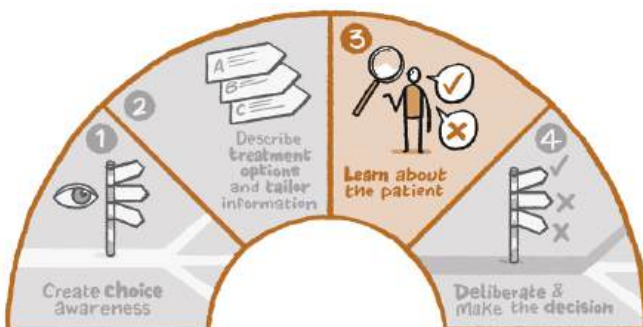
Fixed braces can be harder to clean; clear aligners need to be worn as advised.

Ok and after that...?



Learn about the patient and patient preferences





Clinicians often share *information* and allow patients to ask some *questions*.



Many don't fully explore what is important to us – for example, *activities in my life that I enjoy...*



...and that might become *difficult to continue* because of my disease or treatment.



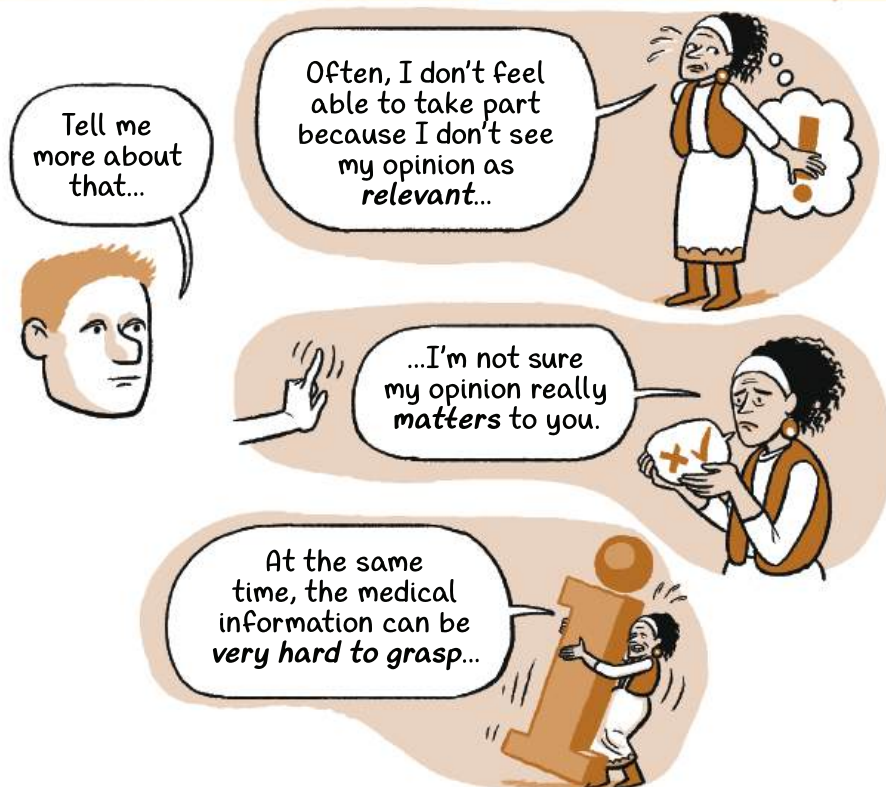
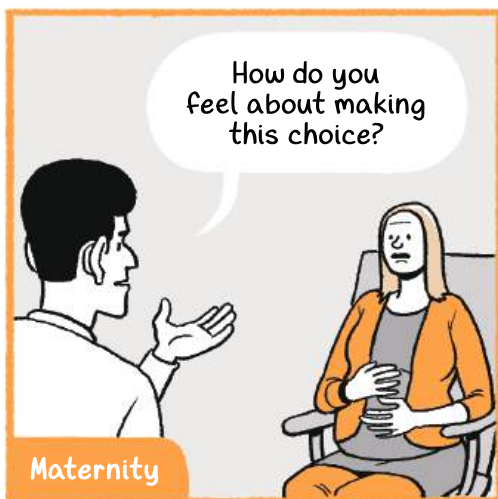
In my experience, *not all patients* want to *participate* in decision making...

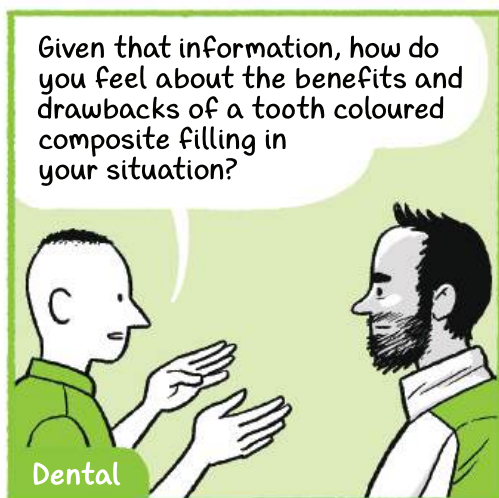
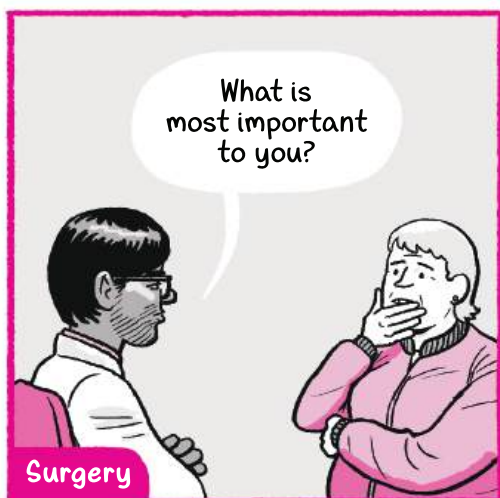
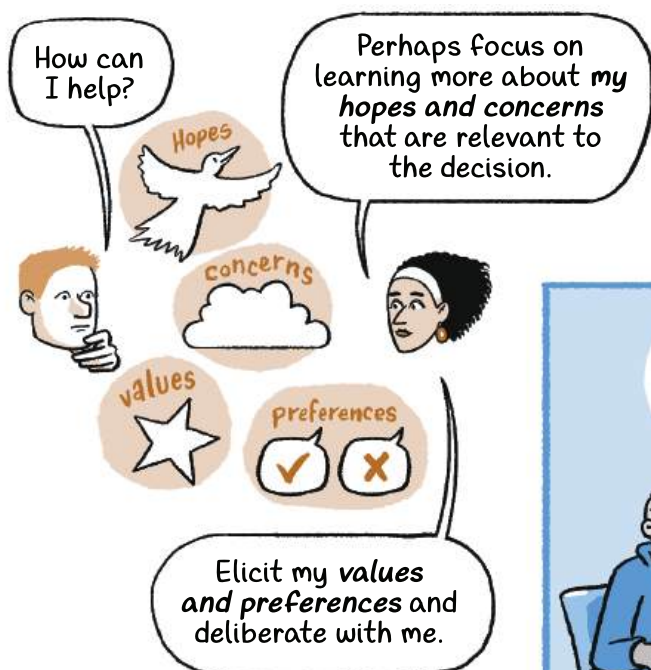


That's true!

Yet this might be because *I don't feel able to*, rather than because I am *unwilling*.





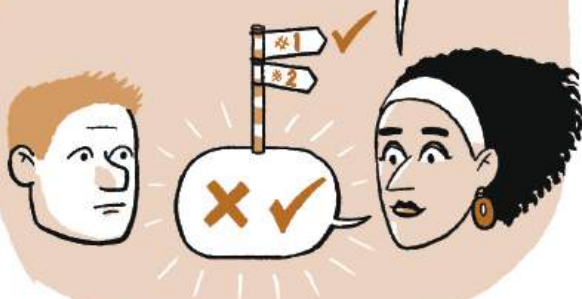


Ok, I think I might need to approach this part of the conversation with some *humility*.



Yes.

To hand over some control and allow *my preferences* to emerge, you have to accept that they are *valuable* in making the decision.



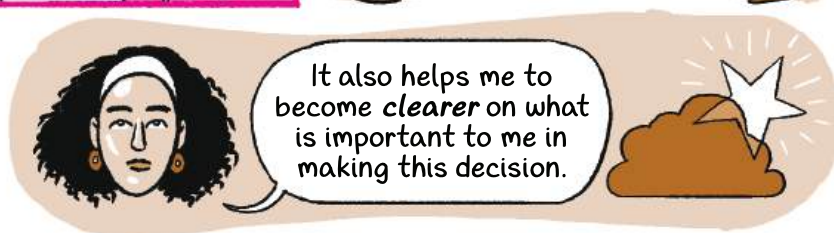
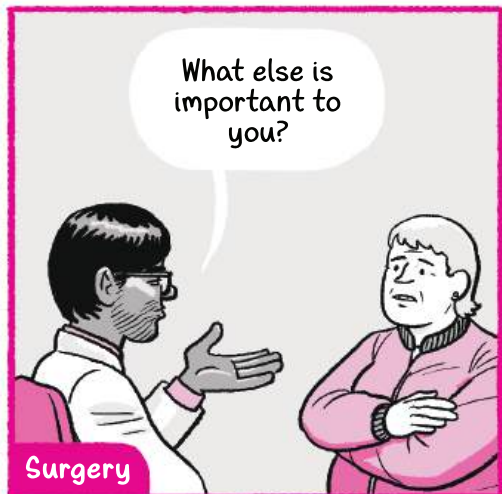
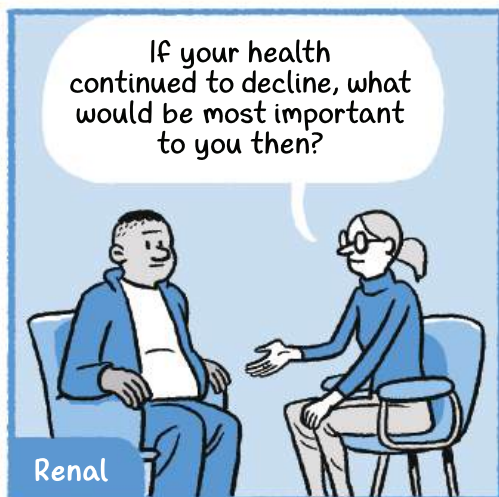
This really changes the way I view my role!

Yes, I can see how that would help.

I know!

We can work on that *together*.





X is very important
for me, but I worry
about Y.



Maternity

Ok, now that I know what
you are worried about, let's
talk about what we can do
to help with that.



Rheumatology

Some patients value being at
home, even if that means they
might live for a shorter time.
Others value...



Surgery

Tell me
more about
that?

When I express
my preferences, you
may need to *explore*
my reasons so you
can understand how
informed those
preferences are.



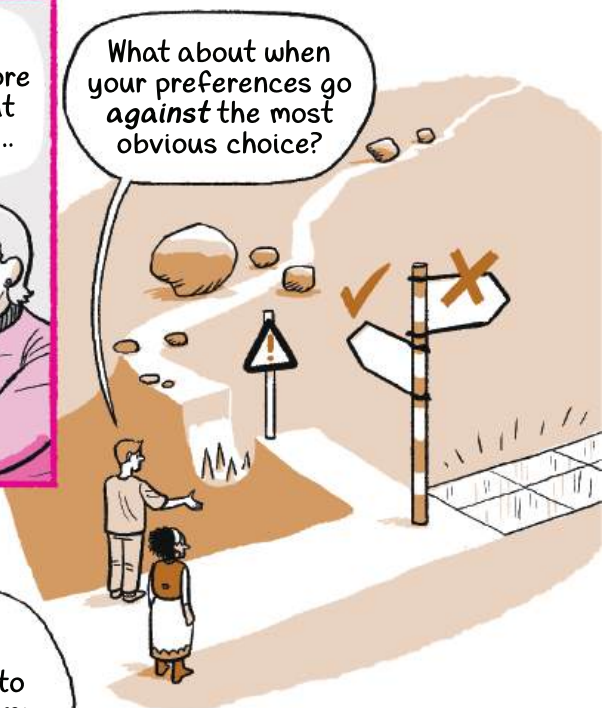
You had already decided for yourself that if chemotherapy could contribute, you would want it.

Tell me more about that...



Surgery

What about when your preferences go against the most obvious choice?



To learn about me and explore my preferences, you need to be *curious about me* – *my perspective* and *my views*.

This may require a certain *openness* from you, so that you feel able to *share information* about your life.



Your *empathy* towards me ensures that I do not feel alone or threatened by your questions.



Listen to me, without judgement, and form **recommendations** that fit with my story.

Maybe you'll need to be **creative** to come up with a recommendation that fits with my situation.

So in this situation, people often want to know what the next few days or weeks are going to involve or look like.

Would you like to talk about that?

Renal

Remember, a **minute spent providing information** may turn out to be less important than...

...a minute spent **waiting silently** for my questions,

...or a minute **responding empathically** to angst and loss,

...or a minute **discussing** when the **plan will be reviewed and revised** if necessary.





Mmmm... I hadn't thought about *time* as a resource like that before.



How do you feel about using a pen injector?

You mean like the one that people with diabetes use?

Yes.



Rheumatology

I've never used one before...



It is also important to think about the *words that you use* when you are describing treatment options to me.



Some ways of speaking are *more supportive* of a shared decision making approach.



Supportive Words ✓

Tell me more...



Pronouncements

Pronouncements are the most authoritative recommendations, delivered without seeking my input.

That doesn't sound good!

No... with a pronouncement, you *declare a treatment option and determine a care path*, usually when *no prior discussion of options* has occurred.

THIS WAY !

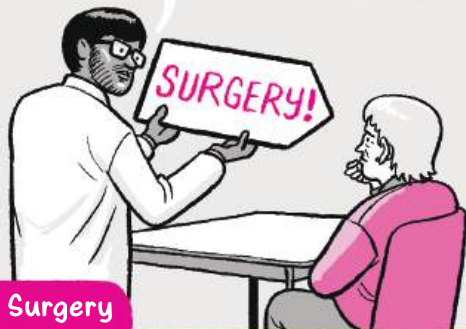
My recommendation for long term contraception and for your heavy periods would be the intrauterine contraceptive device.



Maternity

The first thing we do is surgery.

We do a small surgery to remove just the lump.



Surgery

THIS WAY !

We are going to start you on methotrexate.



Rheumatology

I suppose it's not easy for a patient to go *against* this type of approach.

No. It can even be difficult for me to know what I would prefer, because you have *already* made a *recommendation*.

Ok, so how can I word it?

Shared decision making happens when you ask me about my *preferences* and *values*...

...and then *make* a *recommendation* based on those preferences.

You might use words like...

If you're interested in...

or

I'd like you to think about it.



You are in the timeframe for getting an intrauterine contraceptive device after delivery.



Maternity

That doesn't mean you have to do it, but it does mean that I want to discuss with you what the potential benefits and downsides might be.



It's just so small that I think that you could have a lumpectomy and do just as well with additional chemotherapy...



Surgery

...but, we can talk more about it, the pros and cons of it.



If you're interested in home dialysis, you can start the process this week.



Renal

Before beginning treatment at home, you'll need to complete training, which usually takes about 4 to 6 weeks.



Your nurse can talk with you about what to expect and help you get started.



If you are interested, we could do the screening tests for starting treatment now and my nurse colleague can teach you a bit more about methotrexate?



Rheumatology

It's difficult to formulate a recommendation when a person has so many *different priorities*.

For example, someone who has a serious illness might want to:

Fight the illness

Spend time with family

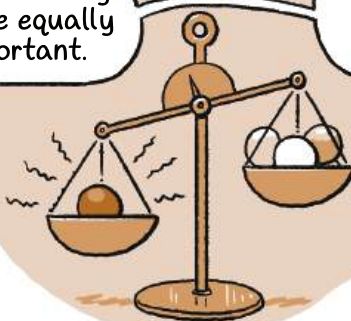
Stay positive

...and die peacefully.

Priorities may not be equally important.

Some weigh more than others.

When you have heard my priorities, you can base your recommendation on the ones most consistent with your assessment of my prognosis and the options available.



Like I said, I'll support whatever you decide.



Maternity

I want to make sure you have clear information about your options...



...so you can choose what feels right for you.



I'll support you in whatever you choose.



Would it be helpful if I offered a recommendation?



Renal

Given what you have told me about what is important to you, I would recommend...



If you felt this was not for you, we could start you on a milder and older drug called Plaquenil.



Rheumatology

It isn't as strong, so the chance of a good response is less, but you wouldn't need blood tests.



If it's a small tumour,
it's fine just to do this
lumpectomy.



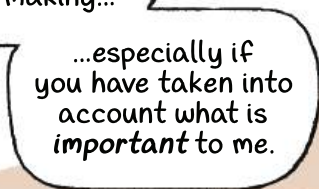
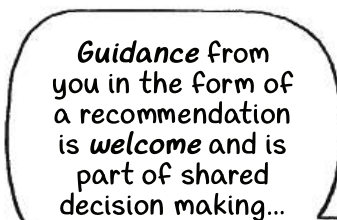
Surgery

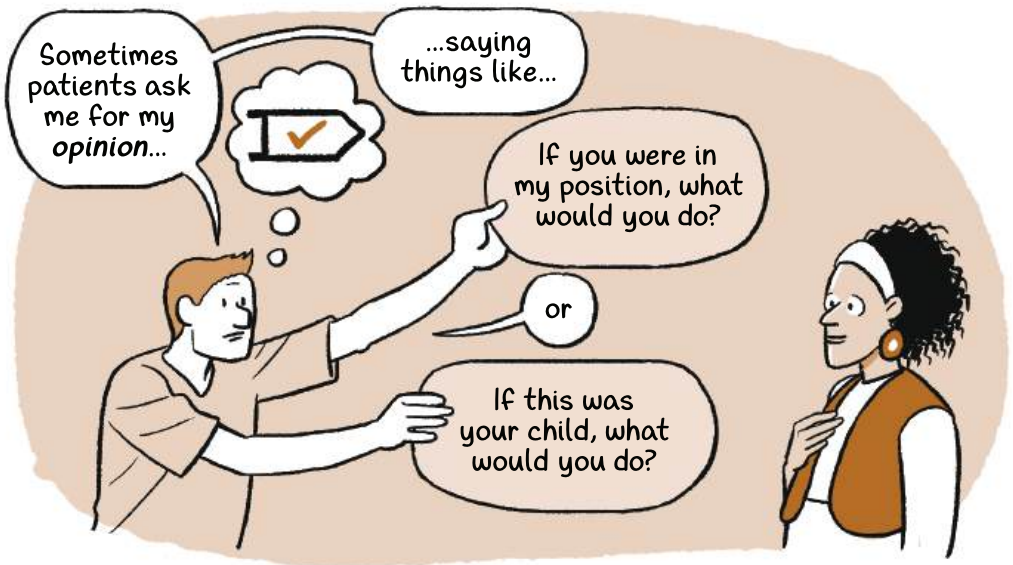
Ultimately,
the choice is
yours.



If you say, 'I really, really
want you to remove my breast.
I'm just so nervous, just
remove the whole thing,'
I would do that.

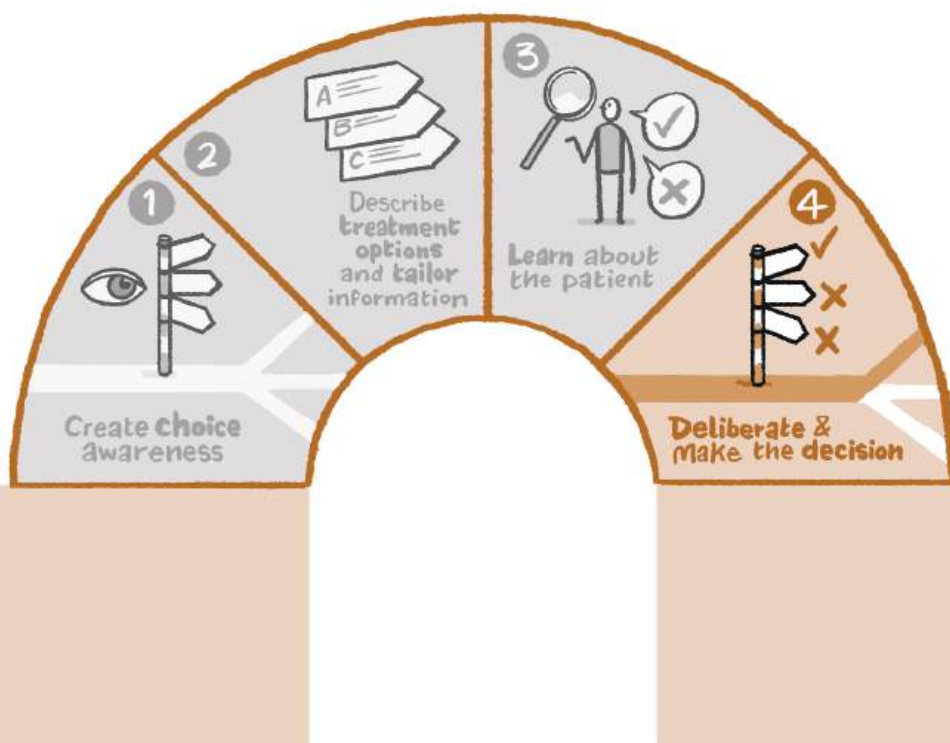








Deliberate and make the decision



To bring the conversation to a close, you might ask me what option I prefer...

...if there is a treatment option that seems most consistent with my values and preferences.



And after that?

Then we either make the decision or explicitly agree to defer it.



We can make the decision together now, or you may prefer to have some time to think and perhaps talk it over with your family.



Maternity

What do you think is best for you?



Maybe you would like to come back with your daughter, and we could have a further chat together?



Renal

We can decide now after you have had a chat with our nurse, or you can go home and think about things, and we can talk over the phone shortly.



Rheumatology

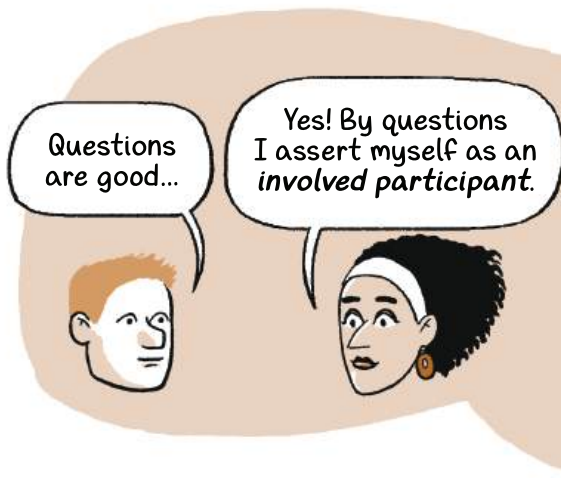
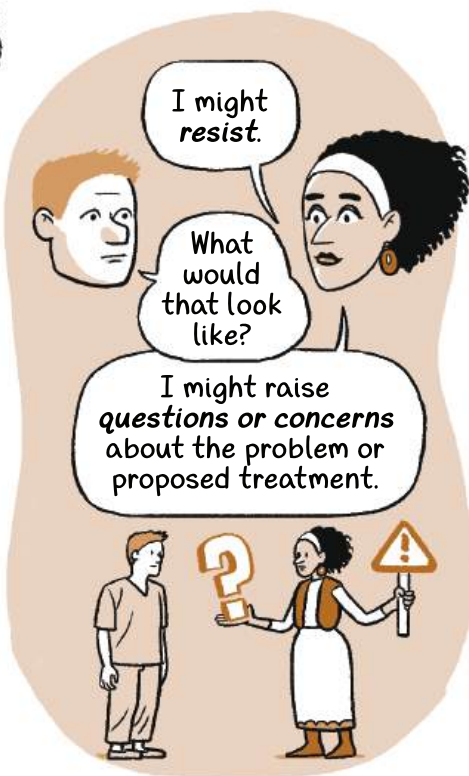
Let's meet again in the afternoon to continue this discussion.



Surgery

In the meantime, here is some information for you to read and discuss with your family.







To foster my involvement you must *listen* to me.



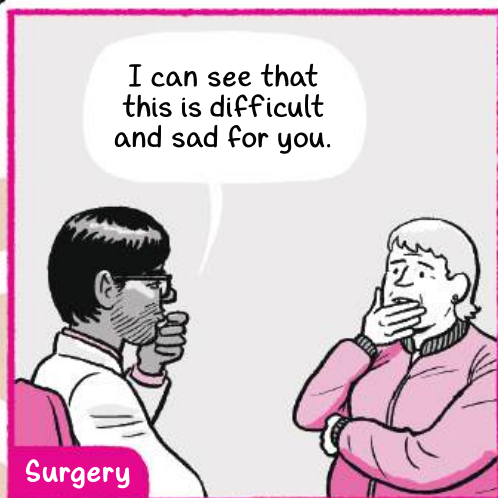
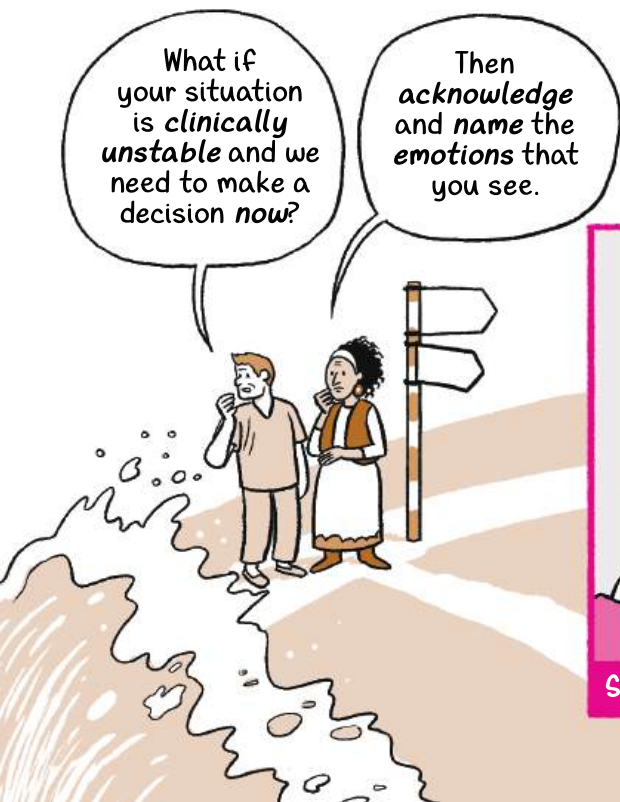
Why?

This will enable you to incorporate my *goals of care* as much as possible.



It will help me to feel comfortable enough to choose *against* your recommendation, without threatening our relationship.





When I feel **overwhelmed**, and a decision needs to be made, you can help by bearing some of the **responsibility** for the decision.



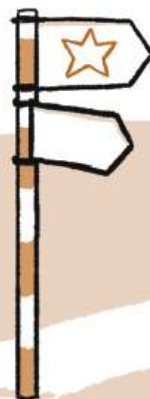
Given what is happening at this time, and how overwhelming all of this is, I wonder if it would be helpful for me to offer a recommendation?



Maternity

What happens if you **don't agree** with my recommendation?

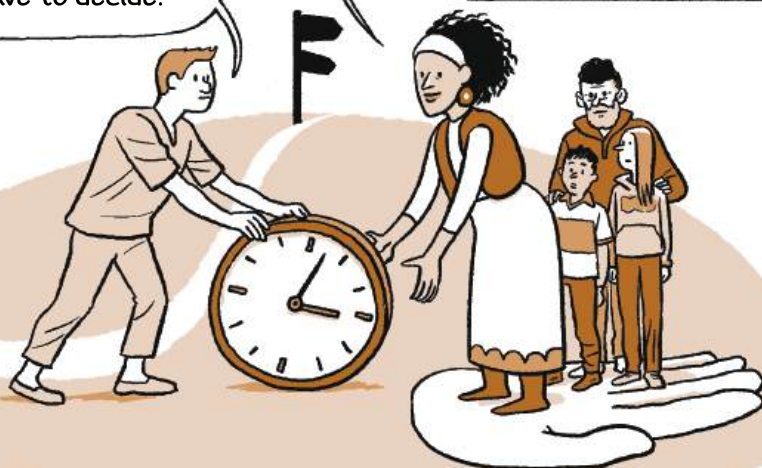
If we have made a **connection**, I will know that I have the option to decline your recommendation.



You might need time to think about it or discuss it with family members. I should let you know how much time you have to decide.

Yes.

It's important that I know whether I need to decide today or whether I have more time, and that you will continue to support me and be involved.



So *flexibility* is an important quality for me to have?

Yes, and *humility*.

I can see how humility would help me to *encourage your preferences* to emerge and to value those as much as my own expertise.



We will continue to work together and figure this out.



Rheumatology

I might not decline, but I might still *feel hesitant* about making the decision.



I'm not sure, I just want to focus on being positive.



Surgery

How can I help?



Acknowledge the values that you are hearing.

You have been so positive through this illness.



Renal

After *acknowledging* this, you can decide whether we need to discuss it further *now*, depending on the *clinical urgency*.



On the one hand, I know that this is difficult to talk about...

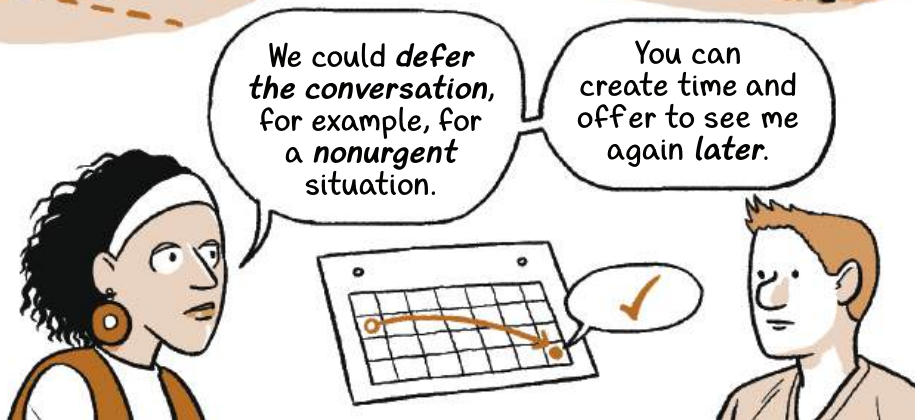
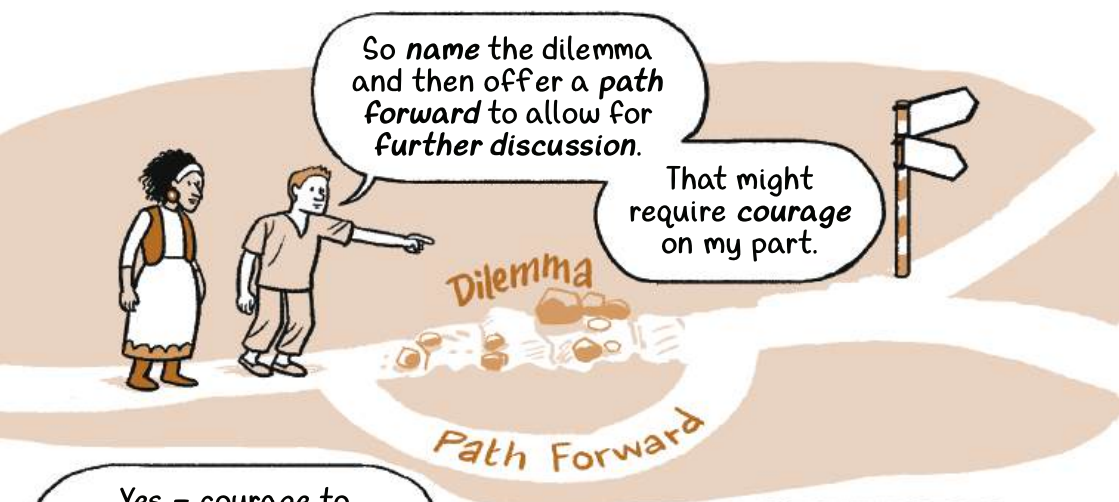
On the other hand I worry that things are changing medically and we need to be prepared...

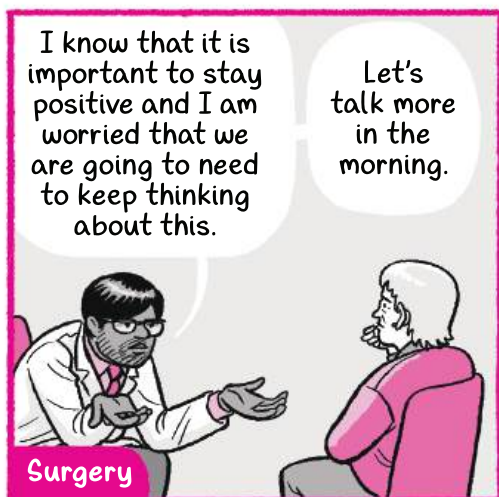


Maternity

Can we talk more about that?







You mentioned some *qualities* that I might need to think about...



Yes, these qualities can be *nurtured* to bridge the gap between *your knowledge and technical skills*...



**Knowledge
and
Technical
Skills**



and *real, authentic efforts to work together* in making decisions about my care and treatment.



**Working
Together**







Document reference number NHCG-D-053-1
Document developed by National Directorate Public Involvement, Culture & Risk Management
Version number V1.0
Document approved by National Healthcare Communication Programme
Approval date V1.0 May 2026
Revision date May 2028

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