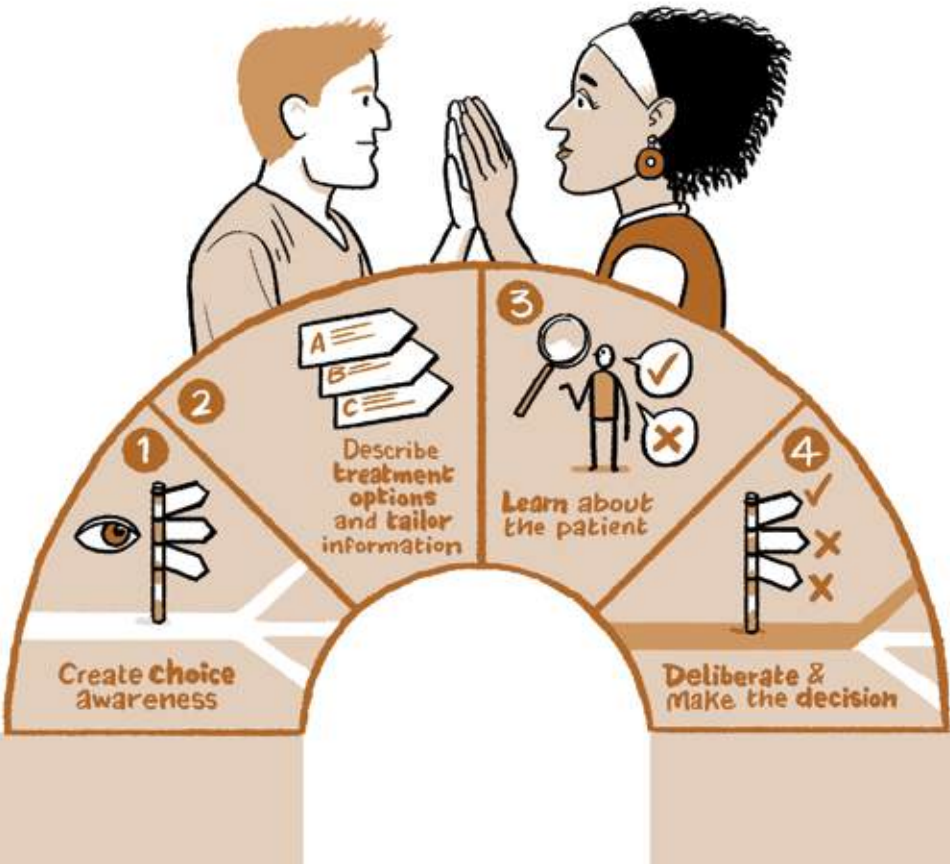


Shared Decision-Making



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



Introduction





So what is *shared decision making*?

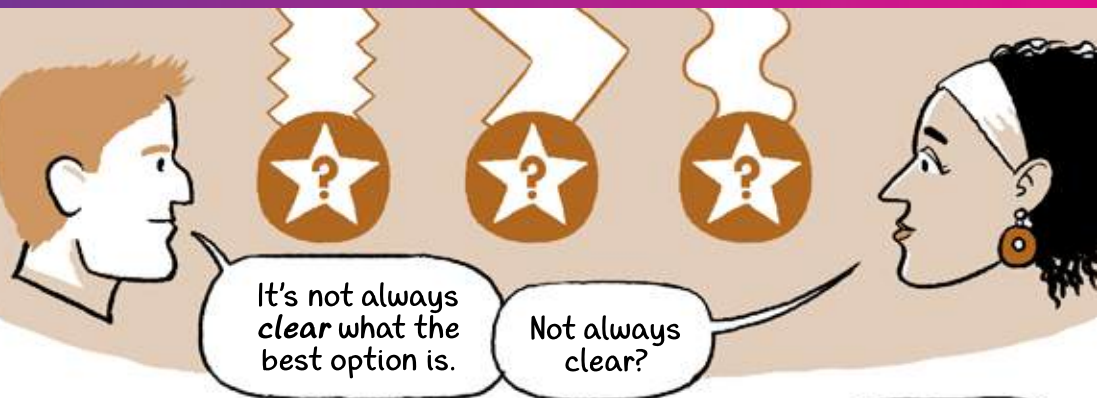
How is it different from the *many conversations* we have about your care?

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.



But even with the best will in the world, you cannot know *what matters to me* until you ask.

What matters to you?



You know the *biology* of my condition, and the likely *benefits and harms* of different treatments.

Yes.

But that alone *isn't enough* for shared decision making.



It isn't?

When I'm ill, I can feel *vulnerable* and might prefer to just go along with what you decide, instead of getting involved.

Shrug





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 relationships.



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.





Shared decision making means we *both* have a role in the conversation.

What is *mine*?

Your role is to:



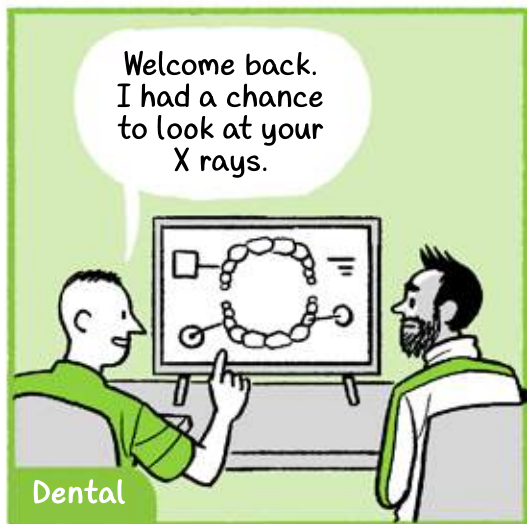
Review the *evidence* and identify the *treatment options* for me.

Explain that a *decision* needs to be made, and that *my preferences matter*.

Share the information *clearly*.

Get to know my *values, goals, and preferences*.

Work with me to develop a *treatment plan* that fits both the *evidence* and *what matters to me*.



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.

Ok.

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



What do you mean?

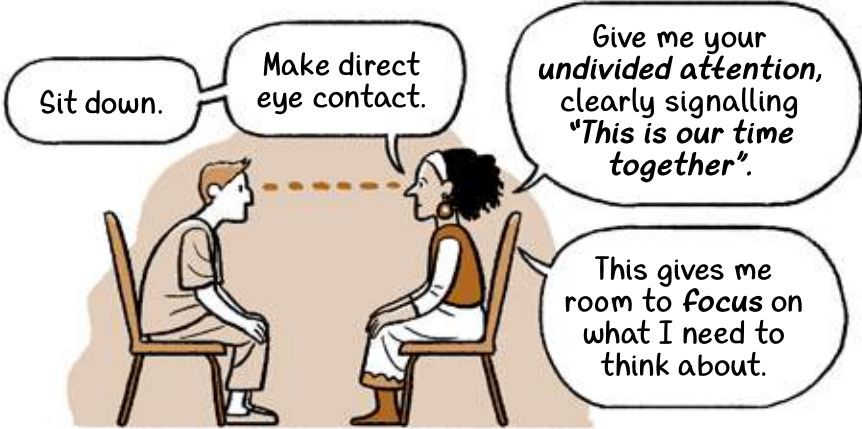
Some decisions can be anticipated *months ahead*.



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

Yes.



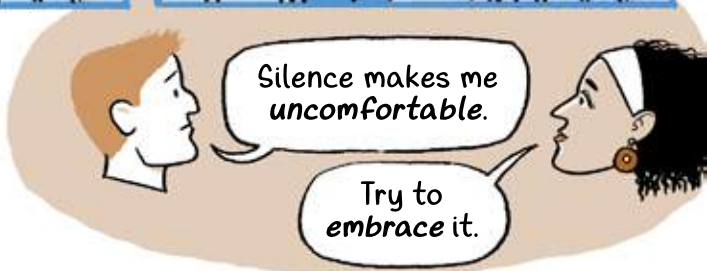


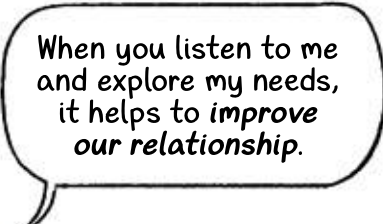
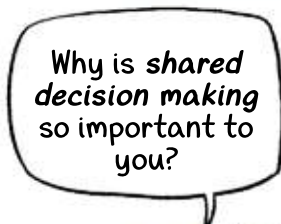


Michael, I've read your notes in detail, but so that I know where to start and what to cover, tell me in your own words what's happened so far?



Renal







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.



Dental

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



Surgery



Ok. I can see how that would help.

It can also be helpful to explore *barriers* with me...

Remember that I am usually the one implementing what we decide, in my own time and with my own *resources*.

I also have to live with the *consequences* of the decision.

You mean for example, any *side effects* that might occur?

Exactly!

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



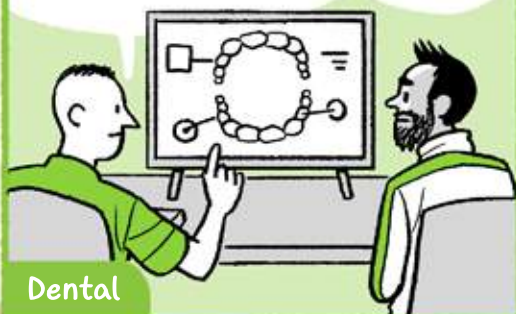
Renal

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...





I am a person
with my own *story*,
values, *preferences*,
worries, *fears* and
hopes.



Ok.

And you still
cannot know
what matters
to me until
you ask.

What's most important to you
about your dental health – for
example comfort, appearance,
or how easy things are
to look after?



Dental

What are your main hopes
and concerns regarding
treatment and your life
moving forward?



Renal



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.



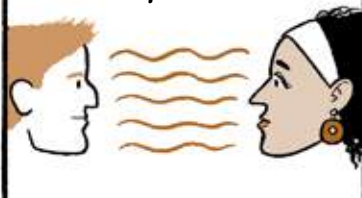
So to help you manage your emotions...



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*...



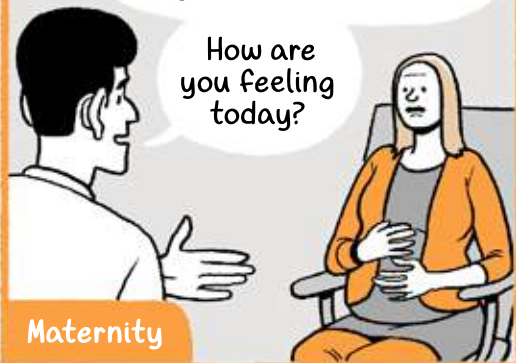
...and maybe giving you some time alone with a *loved one or companion*.





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

How are you feeling today?

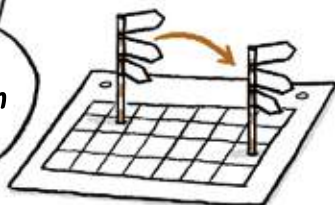


Maternity

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.

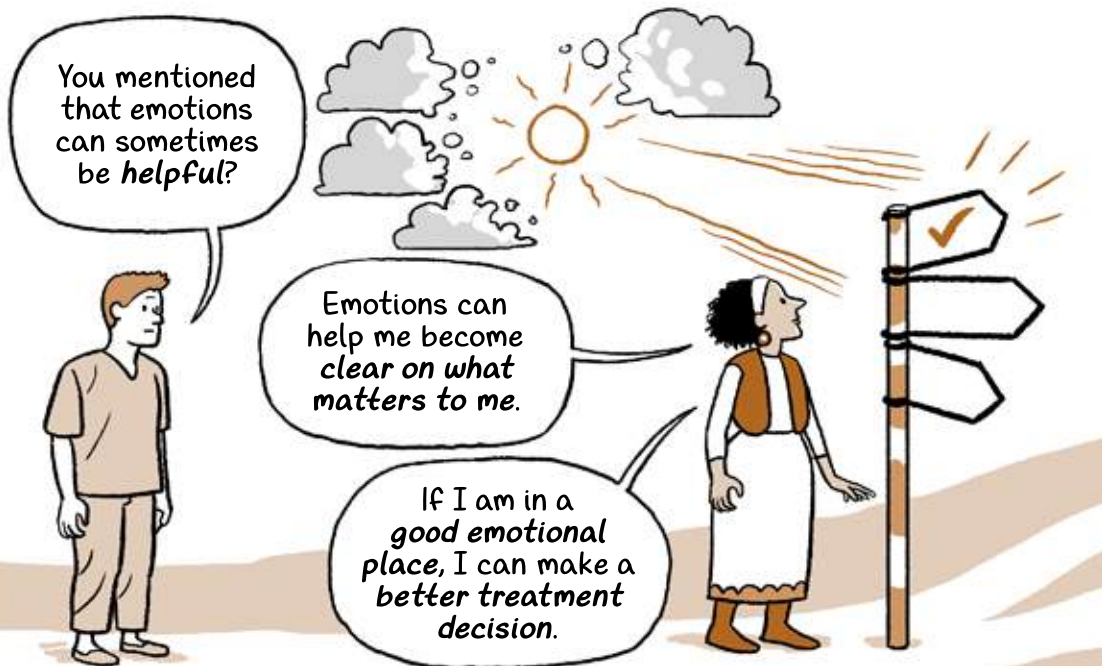


Let's meet again at your next visit to continue this discussion about your options for delivery.

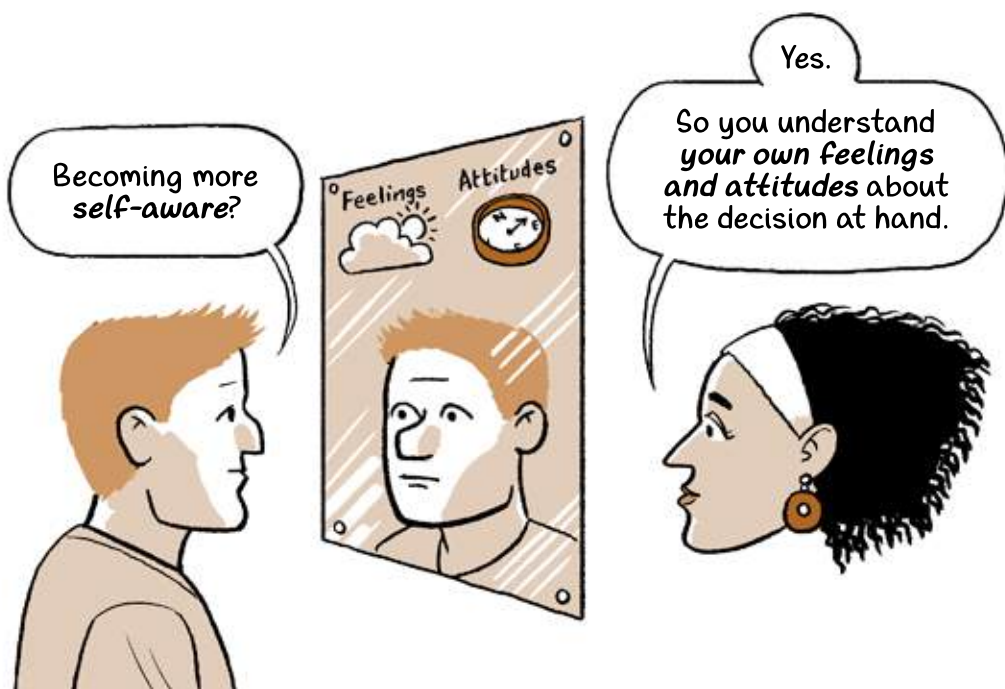
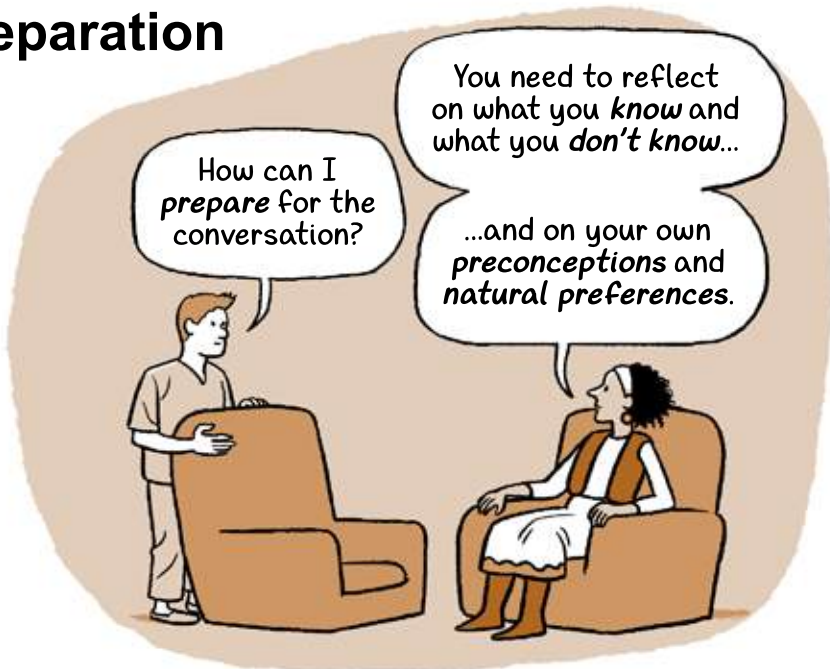


In the meantime, here is some information for you to read and discuss with your partner.





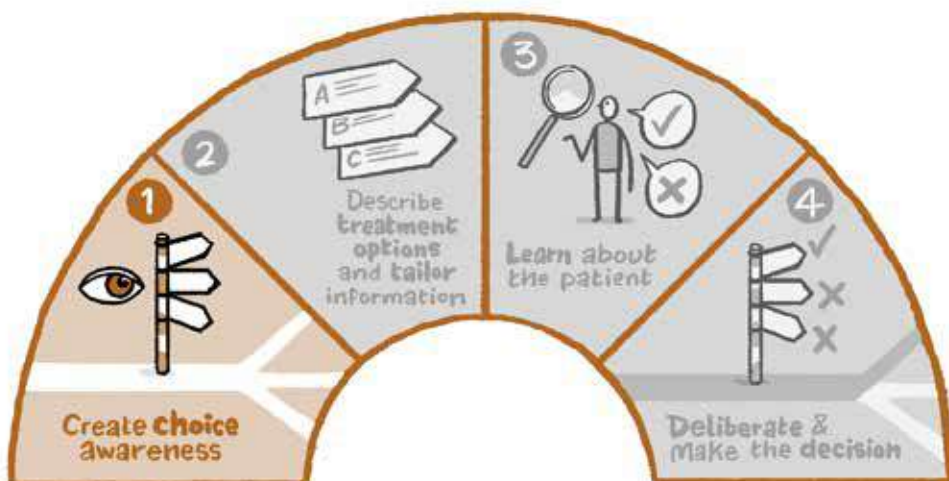
Preparation





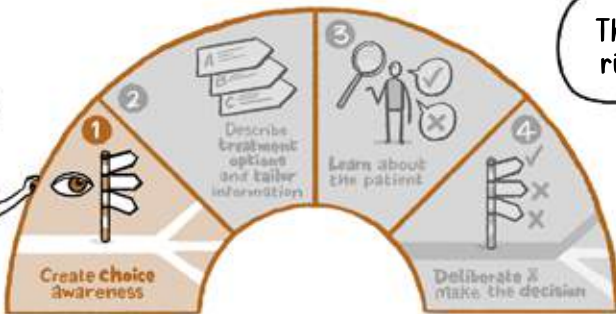


Create choice awareness





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



That's right.



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

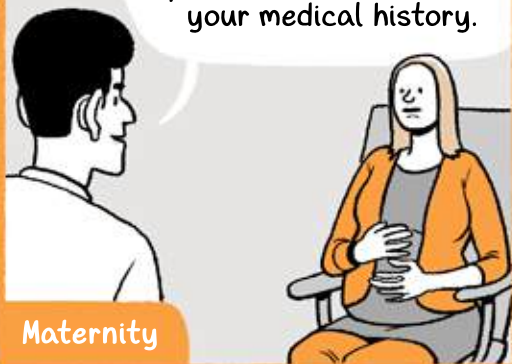


The best option depends not only on the *medical evidence*, but also on *your personal values* and how you want to *live your life*.



Surgery

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



Maternity

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...

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.



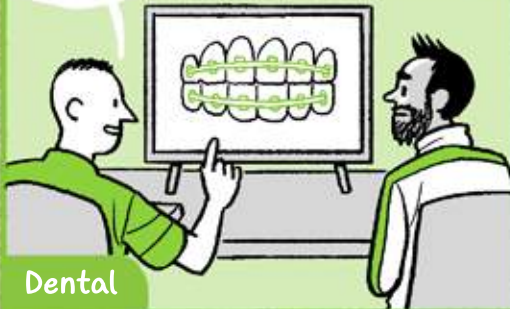
Rheumatology

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



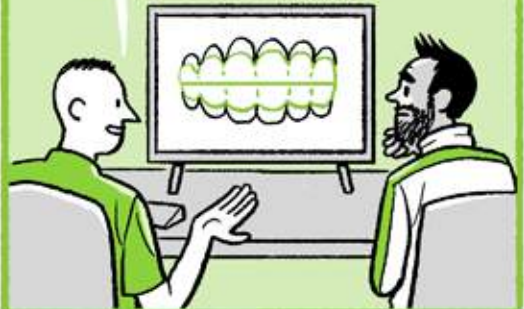
I think there are two main options we should discuss.

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



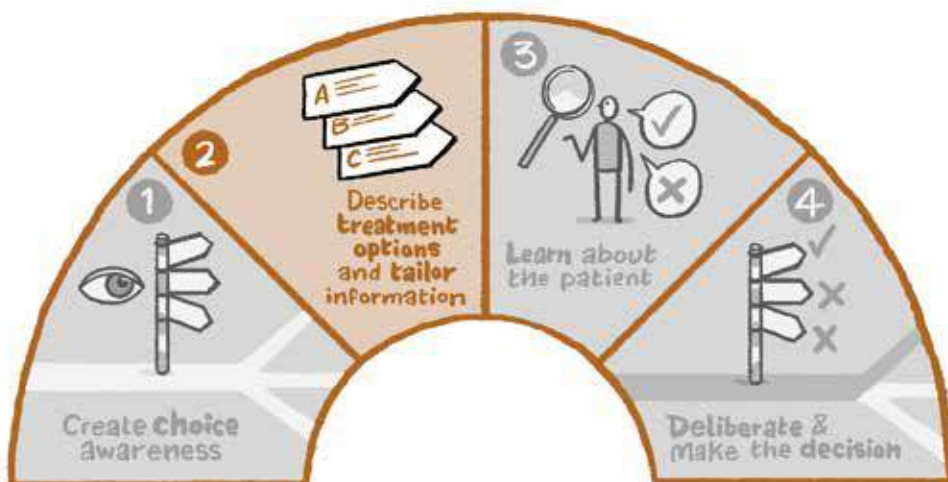
Dental

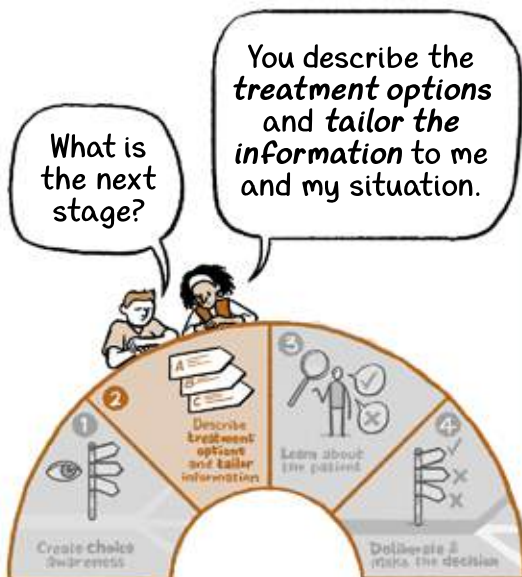
The second is clear aligners, like the Invisalign you mentioned earlier.





Describe treatment options and tailor information to individual patients





What is the next stage?

You describe the *treatment options* and *tailor the information* to me and my situation.

#1

The most common first choice is a tablet called methotrexate.

You need to have regular blood tests while on it.



Rheumatology

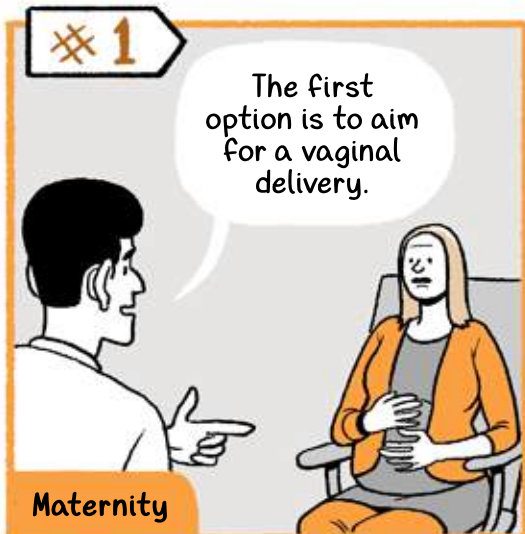
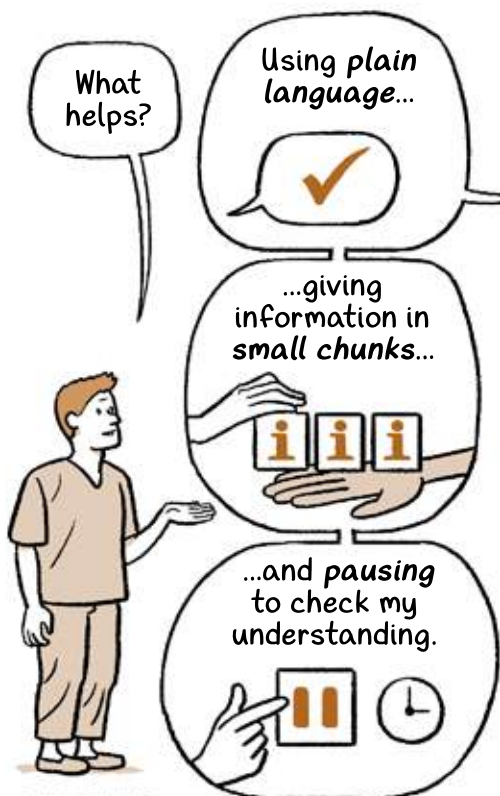
#2

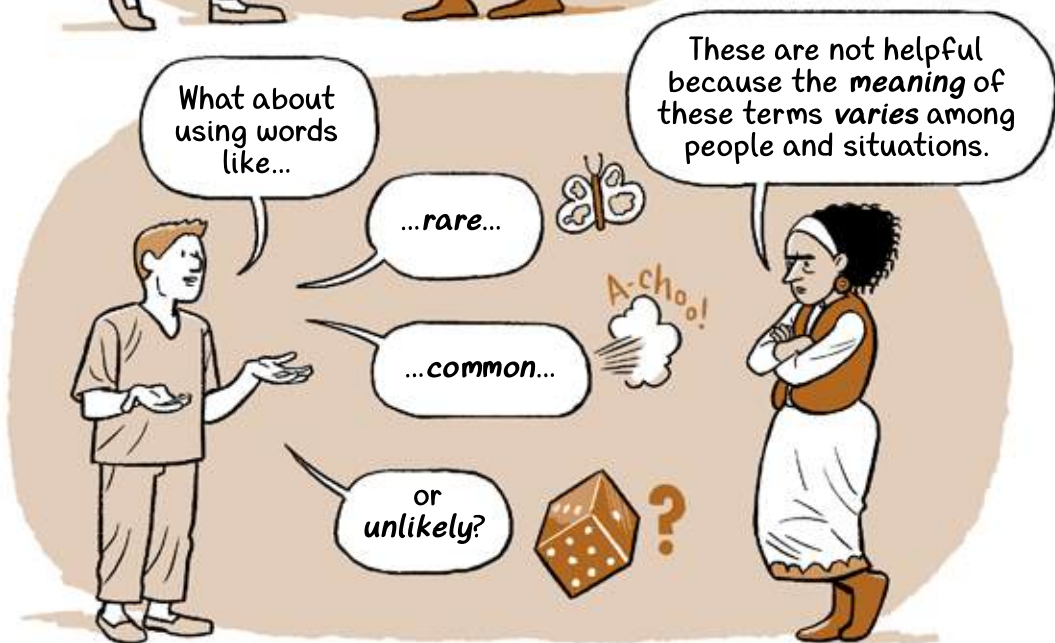
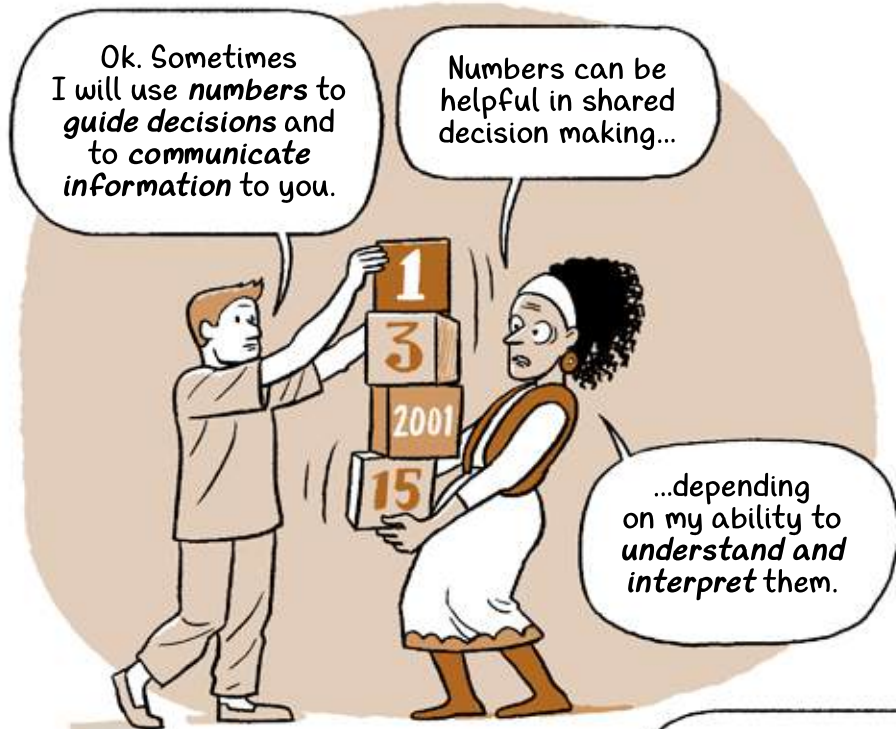
After methotrexate, we have a number of injectable drugs called "biologics."

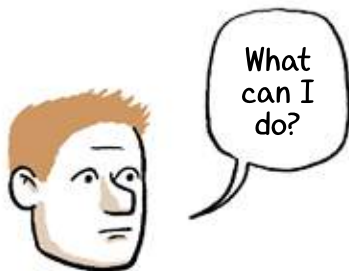


These are newer, and we can teach you about them as an alternative if methotrexate doesn't work.









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...

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

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

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

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?

THIS WAY ✓



Surgery is probably the best option for you.



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.

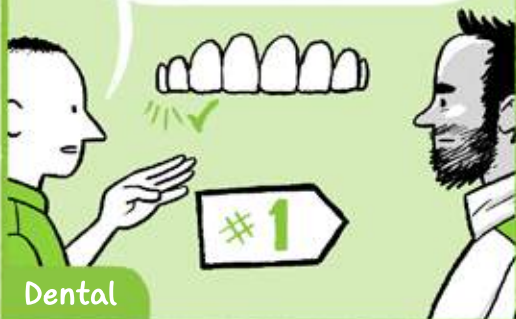


That would require me to be aware of those *framing tendencies* and to be *honest with myself* about them.





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

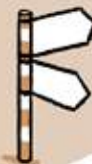


In some situations, there may be other restorative options to consider, and we can talk about what would work best for you.



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.





How do you feel about the side effects of option A?



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?

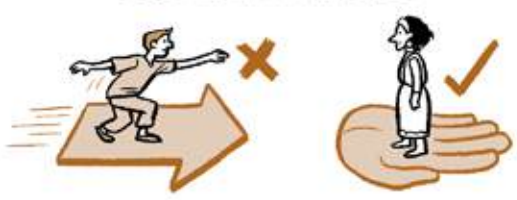
Managing my emotions and behaviour...

What biases should I be aware of?

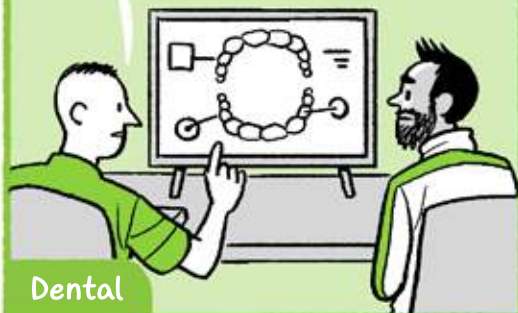


For example, the *availability bias*, which can lead you to overestimate how likely an outcome is (good or bad), because similar examples come to mind easily...

...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.

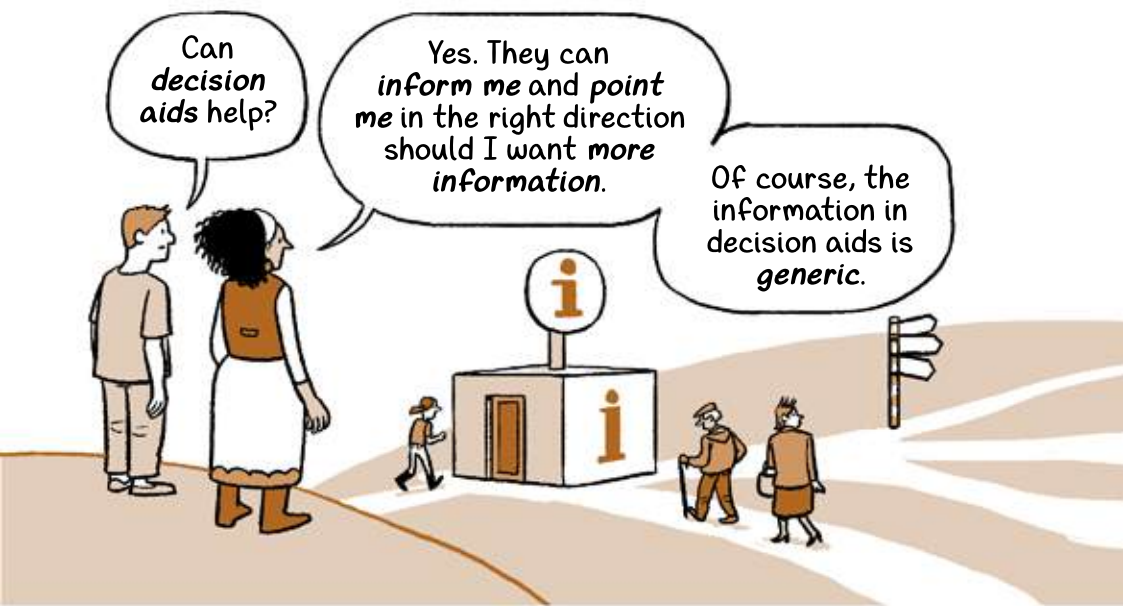


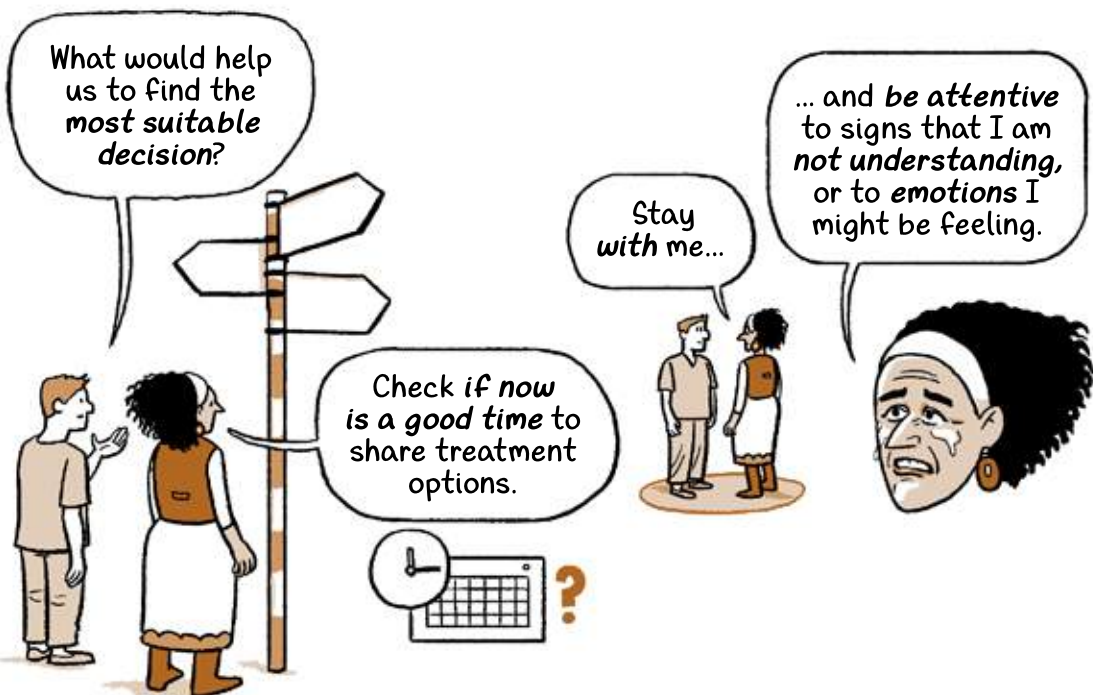
What are your initial thoughts or main concerns?



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

Yes.

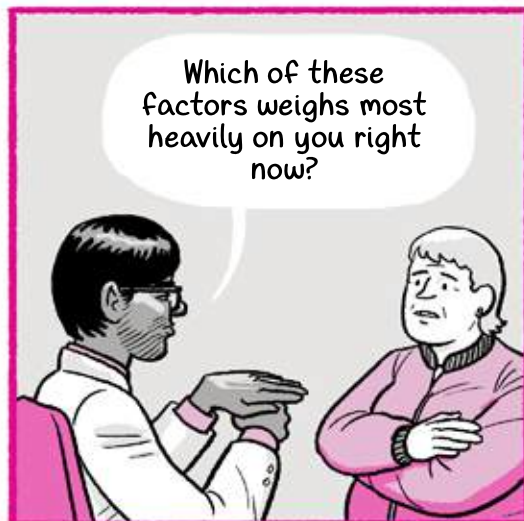
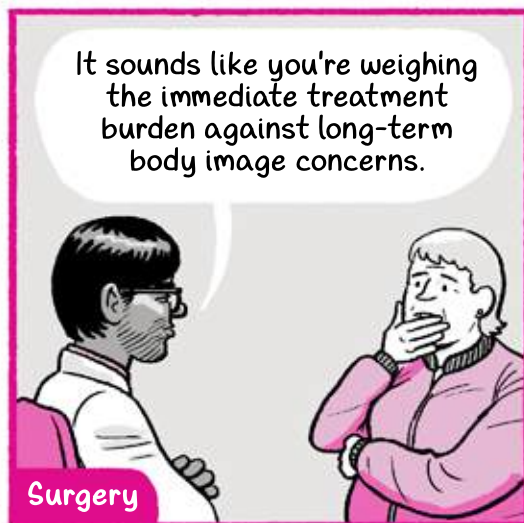




The most common first choice for many women is the contraceptive pill or implant, which we can prescribe or insert for you today.

Maternity

Other options include intrauterine devices, which can be inserted for you now or in six weeks' time...
...or you can use barrier methods such as condoms.



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.



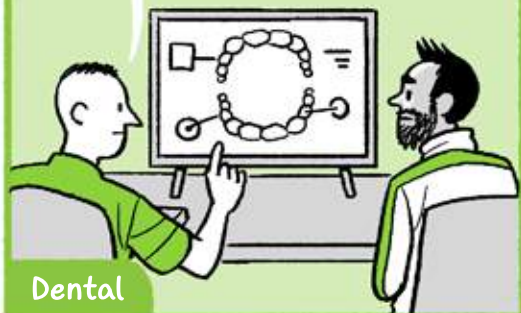
The team are recommending removing the lump and a course of radiation for you.



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.



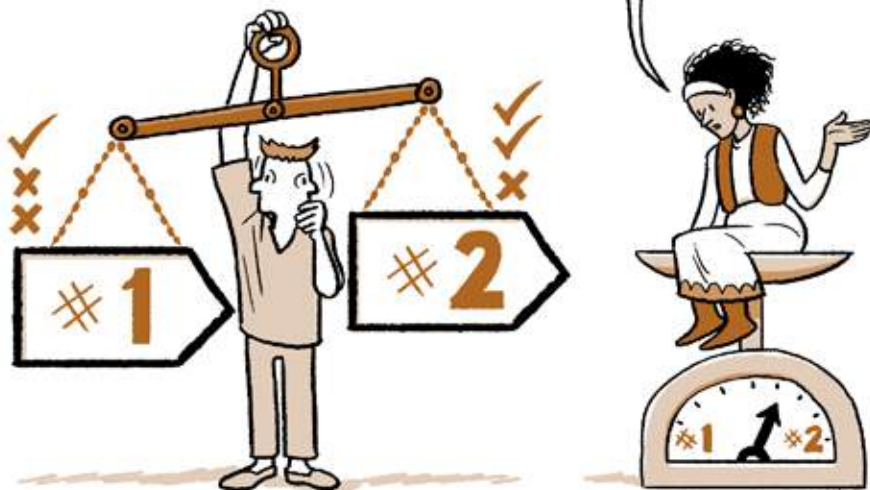
The benefits of home dialysis include more flexibility with your schedule, less travel time and potentially fewer side effects between treatments.



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



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





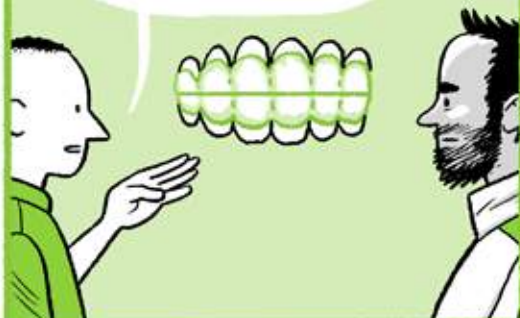
The benefit of fixed braces is that they are very effective for complex movements, including bite correction, and provide a high level of control.

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.

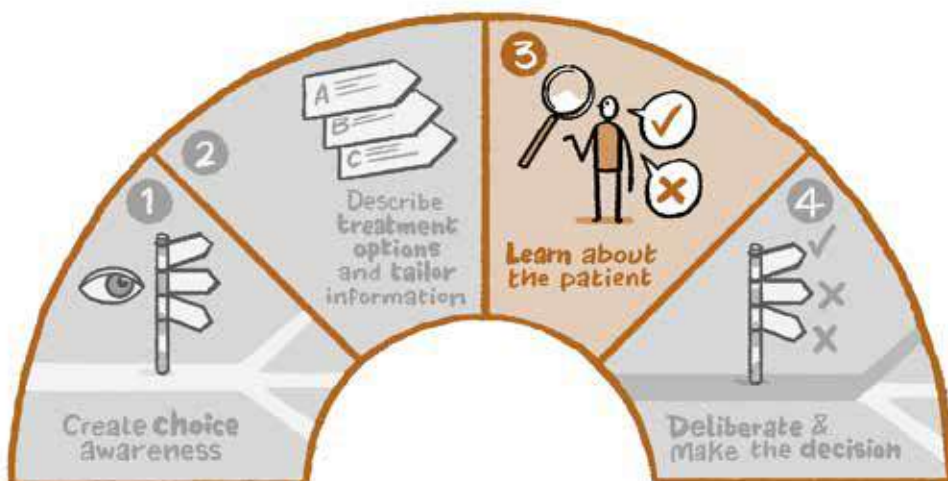


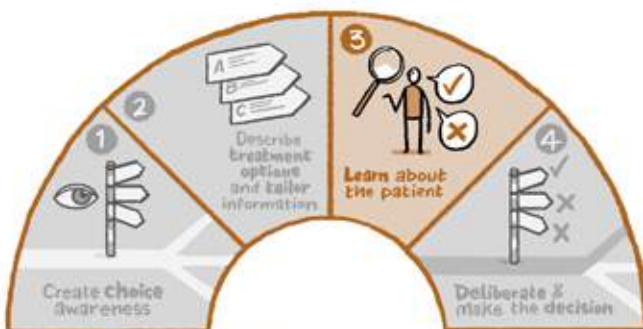
Ok and after that...?





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...



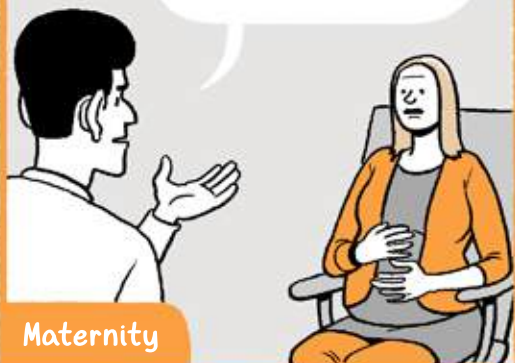
That's true!

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





How do you
feel about making
this choice?



Maternity

What makes
it difficult?

What
would
help?



Tell me
more about
that...



Often, I don't feel
able to take part
because I don't see
my opinion as
relevant...



... or because I
don't understand
the information.



At the same
time, the medical
information can be
very hard to grasp...





How can I help?

Hopes



Concerns



Values



Preferences



Perhaps focus on learning more about *my hopes and concerns* that are relevant to the decision.

Elicit my *values and preferences* and deliberate with me.

What matters most to you?



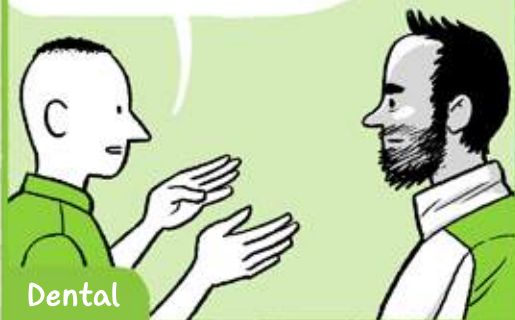
Renal

What is most important to you?



Surgery

Given that information, how do you feel about the benefits and drawbacks of a tooth coloured composite filling in your situation?



Dental



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.



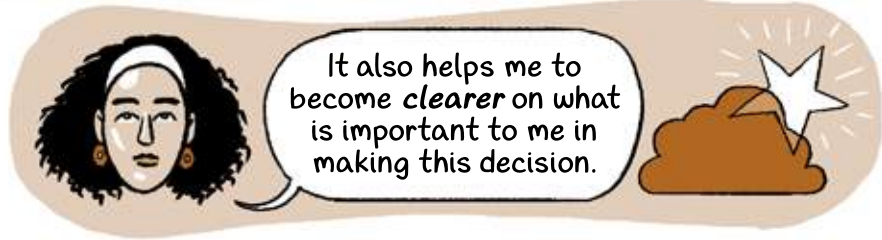
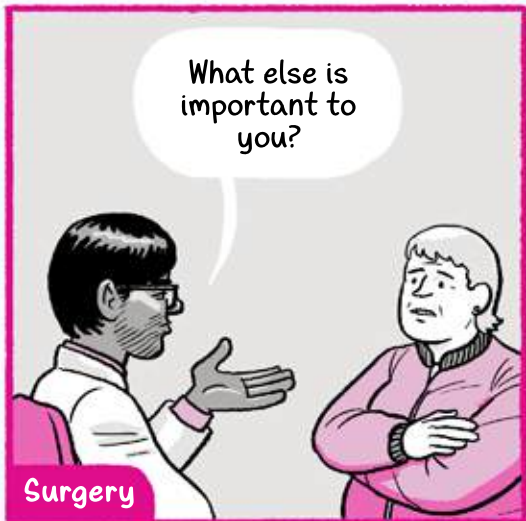
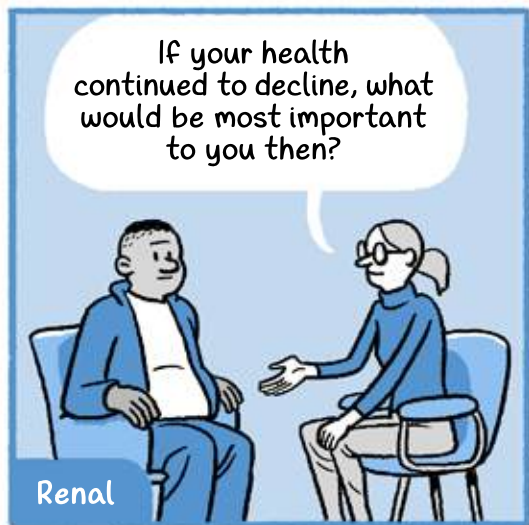
This really changes the way I view my role!

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.



Rationale



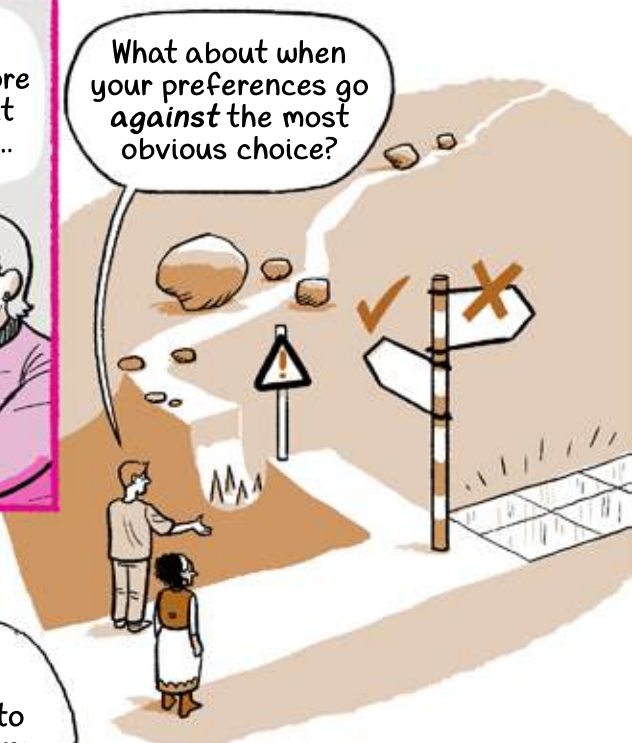
You had already decided for yourself that if chemotherapy could contribute, you would want it.

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.

Will we 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.



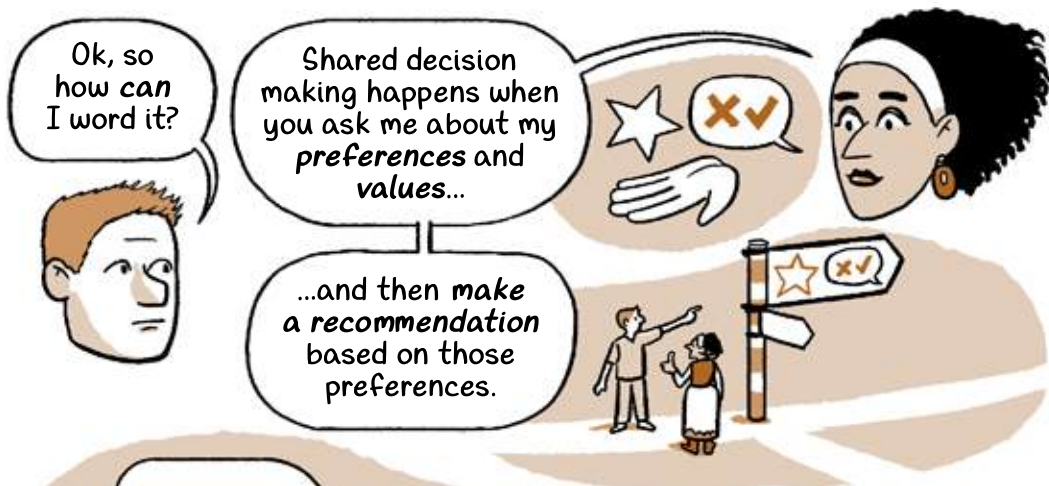
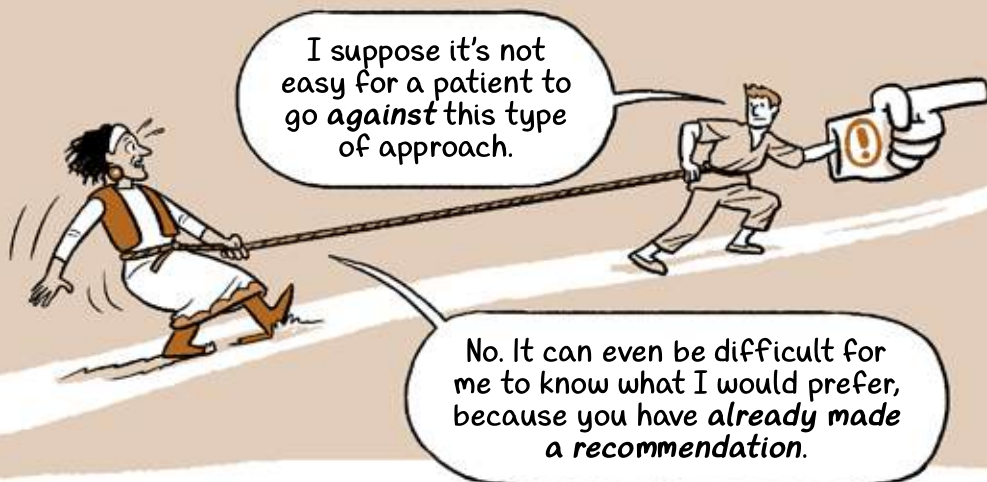
Surgery

THIS ! WAY !

We are going to start you on methotrexate.



Rheumatology





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 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?



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.



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.



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.





Priorities
can *shift*
over time...

That's
true...

...so sometimes decisions
can be *re discussed* and
perhaps *revised* when
priorities change.



I worry
sometimes
that making a
recommendation is
too *paternalistic*
and might infringe
on your *autonomy*.

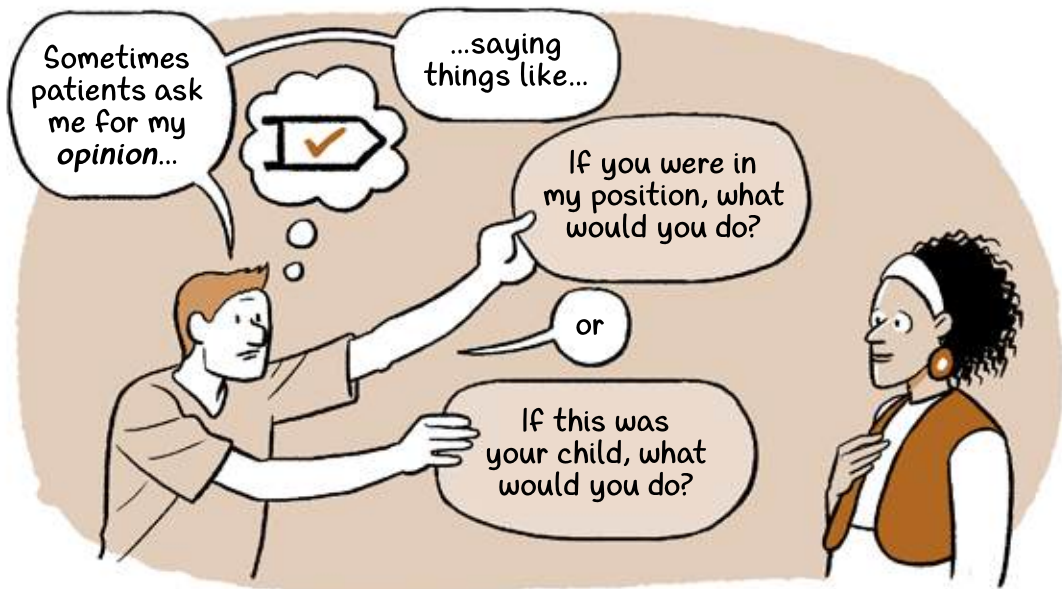
Guidance from
you in the form of
a recommendation
is *welcome* and is
part of shared
decision making...

...especially if
you have taken into
account what is
important to me.



Recommendations
help me to make
decisions that are
more fully informed
by your expertise
and awareness of
likely prognosis
and outcomes.







Try and clarify
what kind of
guidance I need.

Ok.

This might be
more or clearer
information.



Or perhaps I just
want to hear that
my preference is
a **good option**.



Or you might
need help in
clarifying what
is **important**
to you.



That's right.
This helps
me think
further...

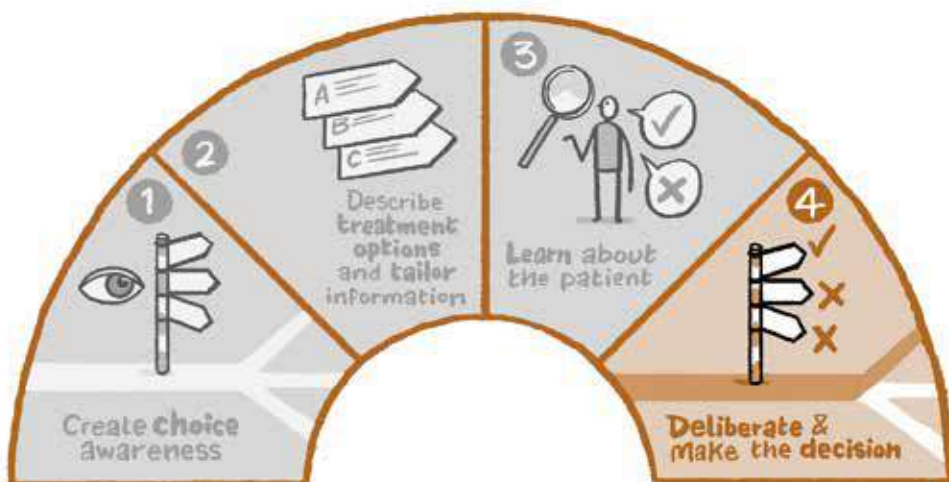


...so I can **better**
understand the decision-
making process in relation
to my own situation.





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.



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.



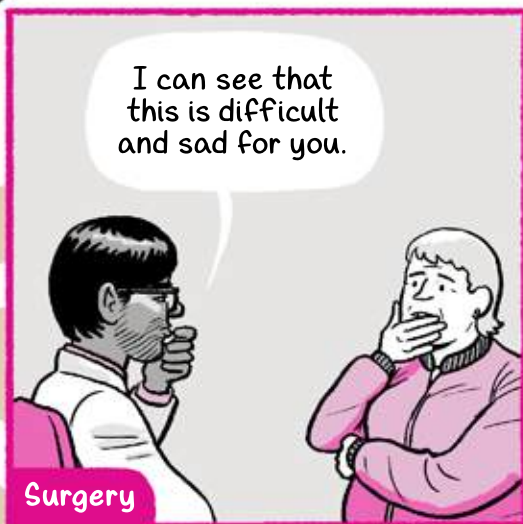
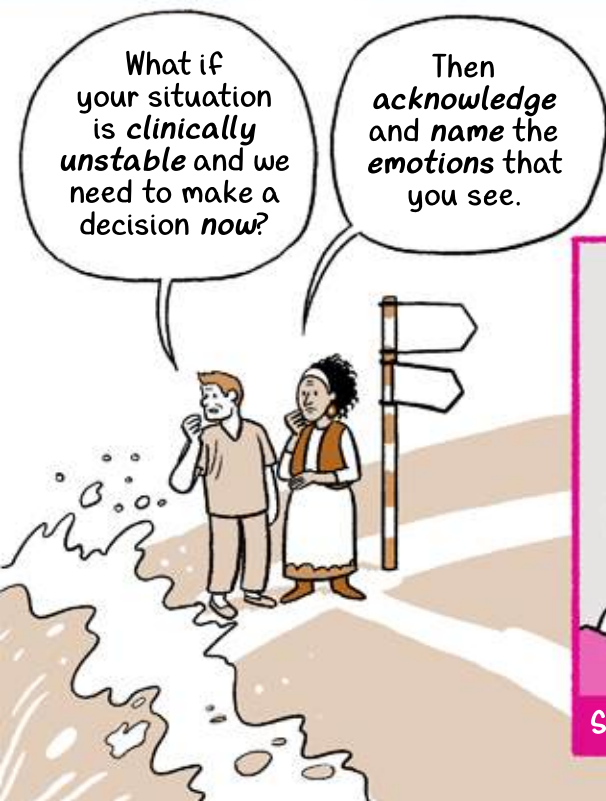
Why?

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?



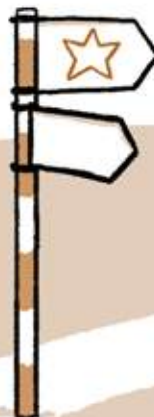
Maternity

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.



Connection

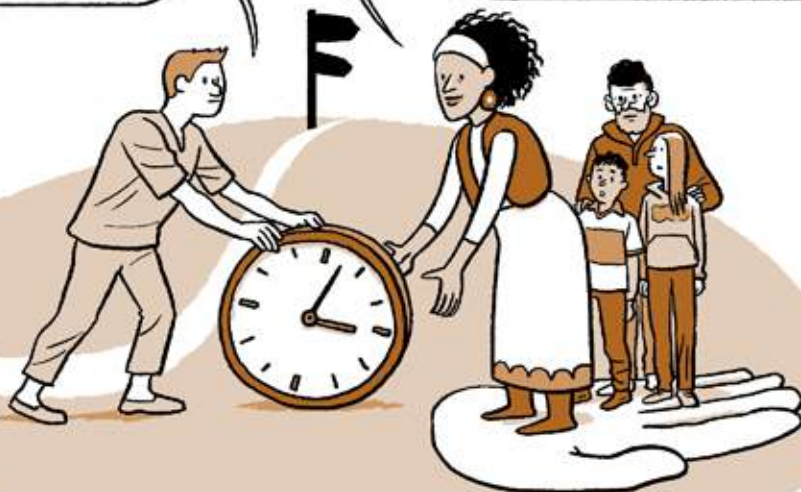




You might need time to *think* about it or *discuss* it with *family members*.

Yes.

It's important that you let me know that it's *ok for me* to take time to think about it, 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...

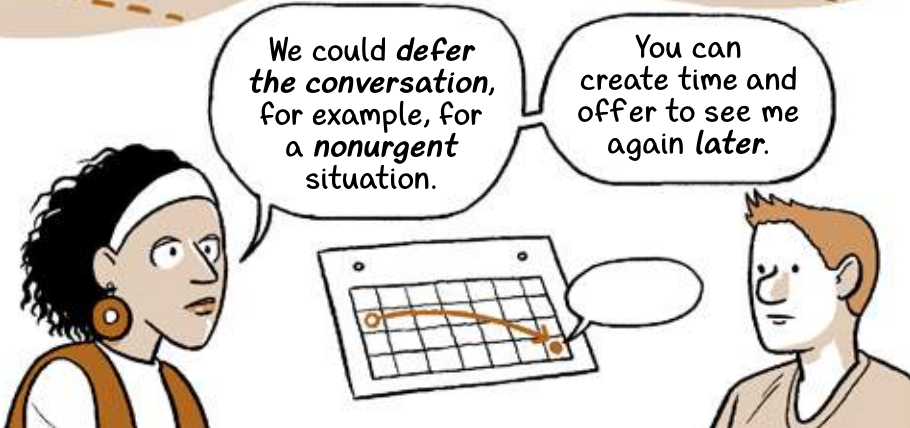
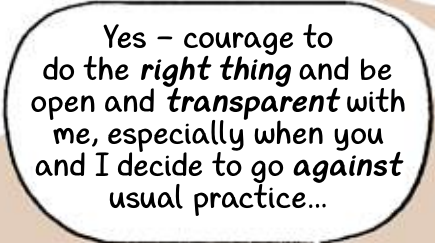
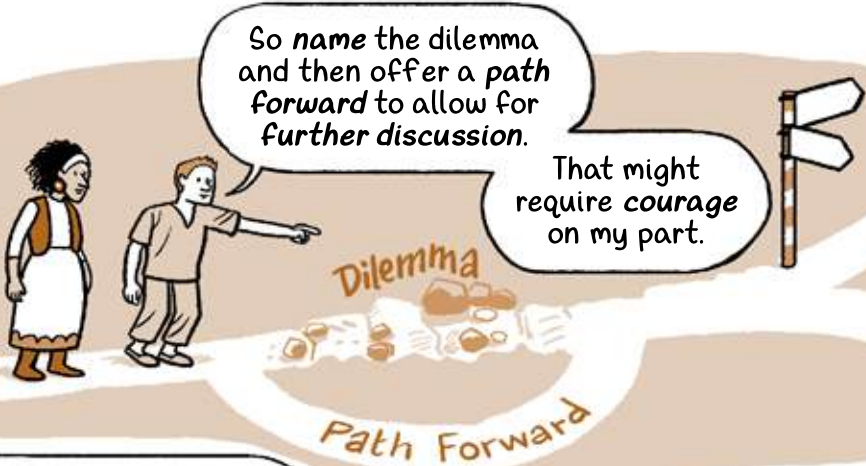
On the other hand I worry that things are changing medically and we need to be prepared...



Maternity

Can we talk more about that?







I know that it is important to stay positive and I am worried that we are going to need to keep thinking about this.

Let's talk more in the morning.



Surgery

It sounds like shared decision making requires *good communication skills*.

Practicing these skills will help.



Yes and at the core, it is a *value*, valuing *partnership* in making decisions together.



Now if I understand you correctly you are inclined to choose...



Rheumatology



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*...



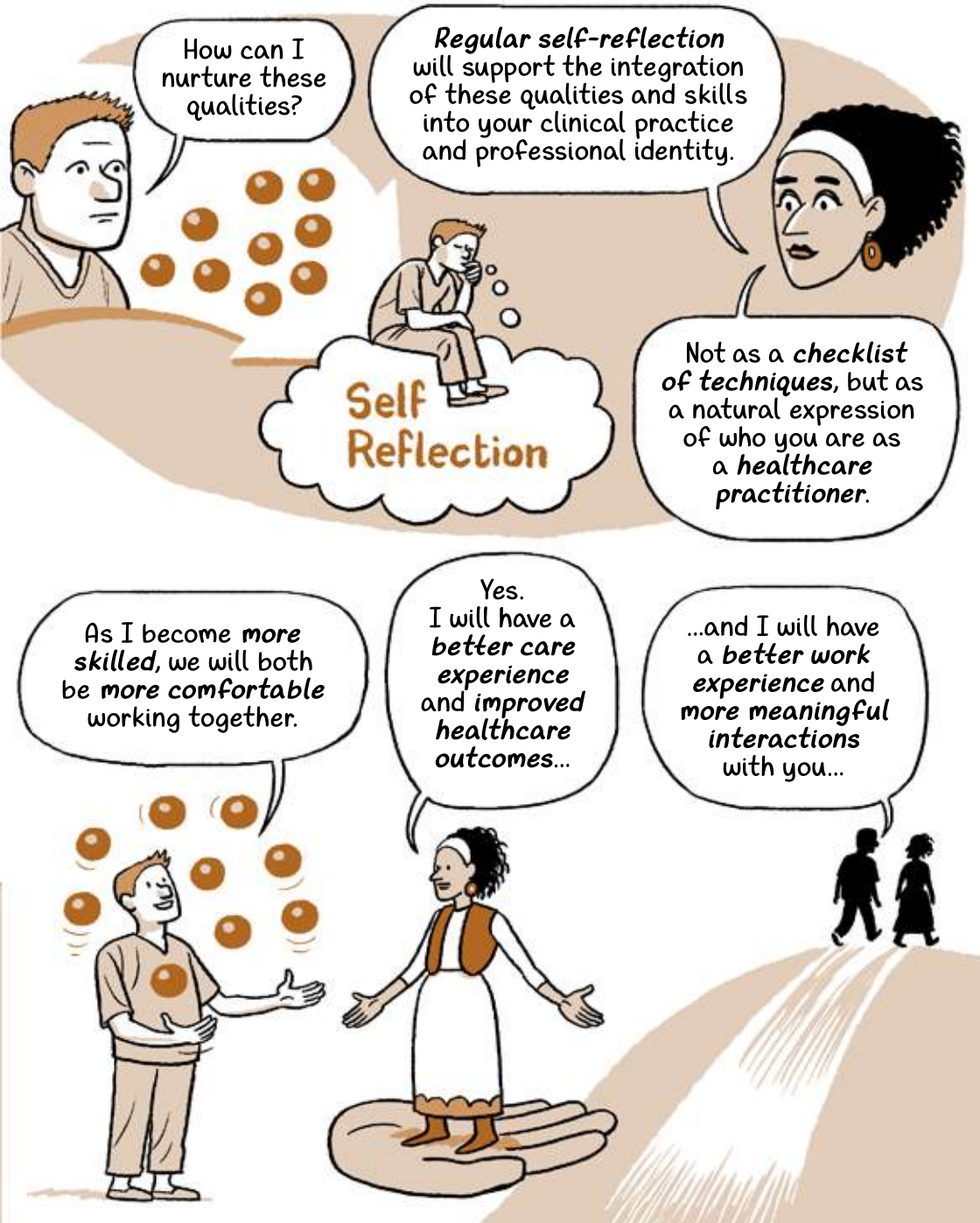
and real,
authentic efforts
to work together
in making decisions
about my care and
treatment.



**Knowledge
and
Technical
Skills**



**Working
Together**



How can I nurture these qualities?

Regular self-reflection will support the integration of these qualities and skills into your clinical practice and professional identity.

Self Reflection

Not as a *checklist of techniques*, but as a natural expression of who you are as a *healthcare practitioner*.

As I become *more skilled*, we will both be *more comfortable* working together.

Yes. I will have a *better care experience* and *improved healthcare outcomes*...

...and I will have a *better work experience* and *more meaningful interactions* with you...





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